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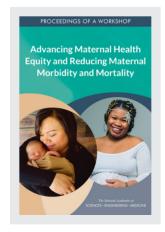
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## Advancing Maternal Health Equity and Reducing Maternal Morbidity and Mortality

PROCEEDINGS OF A WORKSHOP

Joe Alper, Rose Marie Martinez, and Kelly McHugh, *Rapporteurs*Board on Population Health and Public Health Practice

Health and Medicine Division

The National Academies of SCIENCES • ENGINEERING • MEDICINE

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#### PLANNING COMMITTEE FOR A WORKSHOP ON ADVANCING MATERNAL HEALTH EQUITY AND REDUCING MATERNAL MORTALITY<sup>1</sup>

- **CLAIRE BRINDIS** (*Chair*), Distinguished Emerita Professor of Pediatrics and Health Policy and Emerita Director, Philip R. Lee Institute for Health Policy Studies, University of California, San Francisco, School of Medicine
- **ELENA FUENTES-AFFLICK,** Professor and Vice Chair of Pediatrics and Vice Dean for Academic Affairs, University of California, San Francisco, School of Medicine, and Chief of Pediatrics, Zuckerberg San Francisco General Hospital
- MELISSA A. SIMON, George H. Gardner, MD, Professor of Clinical Gynecology, Vice Chair of Research in the Department of Obstetrics and Gynecology, Northwestern University Feinberg School of Medicine, and Founder and Director, Center for Health Equity Transformation
- **BROWNSYNE TUCKER EDMONDS,** Assistant Dean for Faculty Affairs, Professional Development, and Diversity, and Associate Professor of Obstetrics and Gynecology and Pediatrics, Indiana University School of Medicine

Project Staff

ROSE MARIE MARTINEZ, Study Director and Senior Board Director, Board on Population Health and Public Health Practice KELLY McHUGH, Research Associate Y. CRYSTI PARK, Administrative Assistant

Consultant

JOE ALPER, Consulting Writer

<sup>&</sup>lt;sup>1</sup> The National Academies of Sciences, Engineering, and Medicine's planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published Proceedings of a Workshop rests with the workshop rapporteurs and the institution.



### Reviewers

This Proceedings of a Workshop was reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the National Academies of Sciences, Engineering, and Medicine in making each published proceedings as sound as possible and to ensure that it meets the institutional standards for quality, objectivity, evidence, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process.

We thank the following individuals for their review of this proceedings:

**EBONY B. CARTER,** Washington University School of Medicine in St. Louis

JOSÉ F. CORDERO, University of Georgia College of Public Health LORI L. TREGO, University of Colorado Anschutz Medical Campus College of Nursing

Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the proceedings nor did they see the final draft before its release. The review of this proceedings was overseen by **MAXINE HAYES**, University of Washington School of Medicine and School of Public Health. She was responsible for making certain that an independent examination of this proceedings was carried out in accordance with standards of the National Academies and that all review comments were carefully considered. Responsibility for the final content rests entirely with the rapporteurs and the National Academies.



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### Acronyms and Abbreviations

ACA Patient Protection and Affordable Care Act

ACOG American College of Obstetricians and Gynecologists

AWHONN Association of Women's Health, Obstetric and

Neonatal Nurses

CDC Centers for Disease Control and Prevention
CMS Centers for Medicare & Medicaid Services

FQHC federally qualified health center

HHS Department of Health and Human Services

ICU intensive care unit
IHS Indian Health Service

IMI Institute for Medicaid Innovation

MADM Mother's Autonomy in Decision Making MMRC Maternal Mortality Review Committee

MMRIA Maternal Mortality Review Information Application

MORi Mothers on Respect Index

MOUD medication for opioid use disorder

NASDOH National Alliance to Impact the Social Determinants

of Health

xvii

#### ACRONYMS AND ABBREVIATIONS

NBEC National Birth Equity Collaborative NCHS National Center for Health Statistics

NICHD National Institute of Child Health and Human

Development

NICU neonatal intensive care unit
NIH National Institutes of Health
NVSS National Vital Statistics System

OUD opioid use disorder

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PHQ-9 Patient Health Questionnaire-9

PMSS Pregnancy Mortality Surveillance System

PQC Perinatal Quality Collaborative

PREM-OB Scale Patient-Reported Experience Measure of Obstetric

Racism<sup>TM</sup>

PRIORITY Pregnancy Coronavirus Outcomes Registry

PRMR pregnancy-related mortality ratio

RWJF Robert Wood Johnson Foundation

SDOH social determinants of health

SWHR Society for Women's Health Research

USPSTF United States Preventive Services Task Force

V-QPAC Virtual Quality Improvement Prioritization by

Affected Communities

WHO World Health Organization

### Proceedings of a Workshop

#### INTRODUCTION1

The United States faces an alarmingly high rate of maternal morbidity and mortality, a fact that distinguishes this country from other high-income countries that have achieved decreases in maternal morbidity and mortality in recent years. According to 2018 data from the Organisation for Economic Co-operation and Development,<sup>2</sup> the United States ranked 35th out of 36 countries, ahead of only Mexico, and with a maternal mortality rate twice as high as Canada and nearly three times as high as the United Kingdom. In addition, severe maternal morbidity, which includes unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a birthing person's<sup>3</sup> health (Kilpatrick and Ecker, 2016),<sup>4</sup> has been steadily increasing in recent years (Ahn et al., 2020).

<sup>&</sup>lt;sup>1</sup> The planning committee's role was limited to planning the workshop, and the Proceedings of a Workshop was prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine, and they should not be construed as reflecting any group consensus. A list of the planning committee members appears in the Front Matter of this publication.

<sup>&</sup>lt;sup>2</sup> See https://stats.oecd.org/index.aspx?queryid=30116 (accessed August 14, 2021).

<sup>&</sup>lt;sup>3</sup> In general, the National Academies prefers the use of the term "birthing person" as a genderneutral alternative to "women." "Women" will be used when quoting speakers, or to accurately reflect the way that data have been collected.

<sup>&</sup>lt;sup>4</sup> Additional information is available at https://www.cdc.gov/reproductivehealth/maternalinfant health/smm/severe-morbidity-ICD.htm (accessed August 14, 2021).

Hidden within these numbers are large racial, ethnic, socioeconomic, and geographic inequities in maternal morbidity and mortality in the United States. For example, Black mothers are dying from preventable pregnancy-related complications at three to four times the rate of non-Hispanic white women (CDC, 2020), and Indigenous women also face a maternal mortality rate that is two to three times the rate of non-Hispanic white women (Kozhimannil, 2020). Severe maternal morbidity also exhibits racial, ethnic, and geographic disparities (Ahn et al., 2020; Holdt Somer et al., 2017). Furthermore, there are disparities in rates of premature and low-birthweight infants among communities of color (Ratnasiri et al., 2018). These statistics on maternal and health outcomes reveal that there are challenges to protecting both the lives and future health of birthing people and their children.

Recognizing the urgency of this growing problem, the National Academy of Medicine Council expressed great interest in addressing this issue, and as a result, the Board on Population Health and Public Health Practice convened a 1.5-day virtual workshop, Advancing Maternal Health Equity and Reducing Maternal Mortality, to examine the current state of maternal health in the United States and explore the factors needed to enable communities and health care systems to be more effective in reducing maternal morbidity and mortality and in improving outcomes for pregnant people through the fourth trimester. The Statement of Task for the workshop, held June 7–8, 2021, is presented in Box 1.

In his introduction to the workshop, Victor Dzau, president of the National Academy of Medicine, noted that there are numerous factors contributing to these inequities, including barriers to accessing care, a growing prevalence of chronic conditions, maternal stress, inadequate training of health care workers and providers, various social determinants of health (SDOH), and bias and systemic racism that perpetuate inequities in the health care system. He pointed out that because maternal mortality is considered a core measure of social health, one with deep and lasting effects on infant and child health, it is essential to understand the determinants in maternal mortality and to develop effective prevention and intervention strategies.

Recent actions to prioritize maternal health at the federal level, in Dzau's view, represent a step in the right direction toward addressing this problem. In April 2021, the White House issued a presidential proclamation marking the first ever Black Maternal Health Week as part of an effort to highlight racial gaps in pregnancy- and childbirth-related deaths. In addition, the White House has requested \$200 million in the fiscal budget for 2022 to be directed toward maternal health. This budget will be directed toward a number of efforts, including decreasing implicit bias, and funding Maternal Mortality Review Committees (MMRCs) that would review local death data up to 1 year postpartum to inform recommendations the Centers for Disease Control

#### BOX 1 Statement of Task

A planning committee of the National Academies of Sciences, Engineering, and Medicine will plan a 1.5-day public workshop that examines the current state of maternal health in the United States and explores the factors needed to enable communities and health care systems to be more effective in reducing maternal morbidity and mortality and improving outcomes for mother and child through the fourth trimester. The workshop will feature invited presentations and discussions that will explore

- the current state of evidence on maternal health and maternal mortality (and potential future needs for better data collection);
- the factors shaping maternal health and outcomes, including social determinants, and the role early life events play in shaping health trajectories, and access to and the safety and quality of maternal health care;
- current promising evidence-informed practices for improving maternal health and reducing maternal mortality from selected states/health systems (and discuss the potential to scale the approaches);
- promising models and approaches that apply a life course approach to advance maternal health including the health of the child through the fourth trimester; and
- research needs across the life course to improve outcomes for mother and child including preconception through the fourth trimester.

The planning committee will plan and organize the workshop, select and invite speakers and discussants, and moderate the discussions. A proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

and Prevention (CDC) will make. "I think we should all be encouraged by this, and I certainly give credit to this new administration for taking this on and understanding how important it is," said Dzau.

#### Organization of the Proceedings

The structure of the proceedings mirrors the structure of the workshop itself (see Appendix A for the full agenda). The primary sections of the

proceedings reflect the panels from the workshop, and each subsection is dedicated to summaries of individual speakers' presentations, or to the discussion conducted among a group of panelists. The speaker is indicated at the beginning of each subsection.

# EXPLORING THE ROOT CAUSES OF POOR MATERNAL HEALTH OUTCOMES FOR BLACK AND INDIGENOUS PEOPLE

The workshop's first session, which aimed to provide a framing and foundation for the rest of the workshop's discussions, featured three speakers who presented about the root causes of poor maternal health outcomes for Black and Indigenous<sup>5</sup> people. The three speakers were Joia Crear-Perry (National Birth Equity Collaborative [NBEC]),<sup>6</sup> Monica McLemore (University of California, San Francisco), and Marinah Farrell (Changing Women Initiative).

#### The Forces That Shape Inequities in Maternal Health Outcomes

Presented by Joia Crear-Perry, National Birth Equity Collaborative

Joia Crear-Perry began the session by framing the conversation with a vision for the future, rather than coming from a traditional deficit model often used in public health. She explained that her organization, NBEC, operates from the perspective that "all Black mamas, babies, and their villages thrive" by supporting the well-being of all birthing people and those with capacity for birthing.<sup>7</sup> The core values of the organization start with what she called radical joy, and include leadership, freedom, wellness, Black lives, and sisterhood, with a particular emphasis on utilizing collective power to end the inequities that Dzau described in his opening remarks, which affect Black birthing people. "We are going to use our collective power to push for all people being able to thrive in the future," said Crear-Perry.

As a means of grounding the experience of Black communities in the United States, she noted that of the 400 years since slavery began, 86 percent

<sup>&</sup>lt;sup>5</sup> According to the United Nations Department of Economic and Social Affairs, Indigenous refers to peoples who practice unique cultures and ways of relating to people and their environment. They have specific social, cultural, economic, and political characteristics that are distinct from those of the dominant societies in which they live. Examples include Native American tribes and Canadian First Nations. (See https://www.un.org/development/desa/indigenouspeoples/about-us. html, accessed August 19, 2021.)

<sup>&</sup>lt;sup>6</sup> Complete affiliations and titles are available in the speaker biographical sketches in Appendix B.

<sup>&</sup>lt;sup>7</sup> See https://birthequity.org/who-we-are (accessed October 14, 2021).

of those years have been marked by explicit and legal racial oppression (Sealy-Jefferson et al., 2020); 100 percent of the U.S. Black experience has included struggle for equality and recognition of humanity (Sealy-Jefferson et al., 2020). Gaining the right to vote, she explained, did not fix the underlying devaluation of Black lives, nor did laws that enable desegregation, for this devaluation arises from a belief that the hierarchy of human value is based on skin color, gender, religion, or immigration status. "All of those things deeply impede our ability to thrive as a country and as a world, so undoing this devaluation is really how we are getting to a future of justice and joy," said Crear-Perry. In that regard, she explained, achieving reproductive justice<sup>8</sup> requires an analysis of power systems, addressing intersecting oppressions, centering of the most marginalized, and joining together across issues and identities (Shankar et al., 2021).

When Crear-Perry started NBEC 6 years ago, she and her colleagues developed a definition for birth equity: "The assurance of the conditions of optimal births for all people with a willingness to address racial and social inequities in a sustained effort." Achieving this definition, she said, requires teaching this generation and future generations to fight for justice and joy. It also requires putting assurances in place that include both "capital P" policies, such as Medicaid expansion, and "little p" policies, such as those that ensure birthing people have the flexibility to see their physicians on the weekends or at night, because they may have hourly jobs without paid leave.

These policies are critical to achieving birth equity, she explained, because they address the conditions that cause health inequities and create the conditions that will enable all birthing people or people with the capacity for birthing, and not just those who have wealth, 9 to do more than just survive pregnancy—it will allow them to have an amazing experience and thrive. Putting those policies in place will require commitment to addressing racial and social inequities in a sustained manner, which, she noted, will require more than the conversations that occur at this workshop. "So although these 2 days are going to be exciting and important for all of us in this field, we are going to have to sustain this work going forward forever," she said.

Some 15 years ago, when Crear-Perry was the director of maternal and child health for the City of New Orleans Health Department, officials from

<sup>&</sup>lt;sup>8</sup> SisterSong, a Southern-based Reproductive Justice collective composed of communities of color, defines Reproductive Justice as "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities." See https://www.sistersong.net/reproductive-justice (accessed August 19, 2021).

<sup>&</sup>lt;sup>9</sup> Wealth is defined as the current market value of all the assets owned by a household, net of all their debts. In contrast, wealth inequality refers to how unevenly income is distributed across population groups. Wealth inequality has exploded in the United States over the past four decades (Zuchman, 2016).

the World Health Organization (WHO) came to New Orleans to talk about the SDOH that lead to unhealthy behaviors and cause health inequities: having safe and affordable housing, a quality education, social connections, safety, and job security, among others. Crear-Perry said,

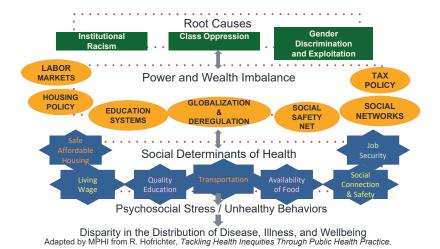
It is not that Black and brown people are broken or that Indigenous people are making bad choices or have different kidneys, lungs, or pelvises, but it is these social determinants of health that are causing the maldistribution of disease, illness, and also well-being.

Crear-Perry says that, though the idea of the SDOH has led the world, public health, and health care to "finally stop blaming and shaming individuals," this acceptance has not consistently led to honest conversations about the origins of those social determinants. She explained that power and wealth imbalances affect labor markets, housing policy, educational systems, social networks, and other factors that create the SDOH. But underlying this power and wealth imbalance are institutional racism, class oppression, and gender discrimination, and gender exploitation as the root causes of inequity (see Figure 1). In some places, religious fundamentalism, casteism, and tribalism are also important root causes. While it is important to address the SDOH, said Crear-Perry, "if we do not undo these root causes, we will make programs around these social determinants of health, but not undo the harm, the root injury that caused them in the first place."

WHO defines the SDOH as the "circumstances in which people are born, grow up, live, work and age," <sup>10</sup> a definition that Crear-Perry said is widely known. However, the definition goes on to explain that those circumstances are shaped by the distribution of money, power, and resources at the global, national, and local levels, with examples or resources including employment, housing, education, health care, public safety, and food access; it is this second part of the definition, said Crear-Perry, on which the field of maternal health must focus. "If we are going to see maternal health outcomes improve, we have to undo these social determinants of health inequities," she said.

As an example, Crear-Perry pointed out that it is now commonly understood that a lack of transportation is a social determinant of health. To address that, public health and health care systems are providing birthing people with ride-share vouchers, which Crear-Perry regards as a positive step. "But if we really want to undo the root causes, we would acknowledge the history of redlining, acknowledge the history of neighborhood covenants, and we would understand that segregation was by law," she said, and it was because of this

 $<sup>^{10}</sup>$  For more information, see https://www.who.int/health-topics/social-determinants-of-health (accessed August 17, 2021).



**FIGURE 1** The many factors of the root causes of health inequities. SOURCES: Workshop presentation by Crear-Perry on June 7, 2021; adapted from Hofrichter and Bhatia, 2010.

deep history of segregation and racism that communities of color disproportionately do not have ready access to public transportation. Undoing the root cause of differential transportation access, one contributor to health disparities, requires rebuilding American transportation networks.

In line with this approach, when birthing people or people with the capacity for birthing come to their obstetrician, Crear-Perry said that more attention should be paid to social risk factors in addition to clinical risk factors for morbidity and mortality. A practitioner should consider: Does that person have access to air conditioning, given that heat exhaustion increases the risk of birth injury? Are they food insecure? Does their work schedule enable them to make twice weekly nonstress testing that has been shown to improve birthing outcomes (Boehm et al., 1986)?

Crear-Perry noted that when she first learned that Black birthing people were dying at three to four times the rate of their white counterparts, or at 8 to 12 times the rate of their white counterparts in New York City (Boyd et al., 2010), she predicted that the response would be to "blame and shame" Black birthing individuals, with accusations such as "they're so fat, and they don't listen. They're so noncompliant. They don't go to the doctor, they don't get married." However, the data showed that Black mothers who were college educated fared worse than women of all races and were five times more likely than non-Hispanic white women to die within 1 year of childbirth (Angley et

al., 2016). In fact, obese women of all races had better birth outcomes than Black women with normal weight, and Black women who initiated prenatal care in the first trimester still had higher rates of infant mortality than non-Hispanic white women. Crear-Peary said,

The truth is, we have lots of programs, and we do all these things, and we are still more likely to die. So if we leave these 2 days [of the workshop] and all we come out with is, "if only they would just go to the doctor and exercise and eat more kale," we have lost the point of undoing the structural racism, the inequalities in this country that harm and devalue people of color.

Racism, she explained, affects health directly, such as through chronic stress, as well as indirectly. The indirect effects arise from race-based discrimination, which occurs in multiple systems and leads to differential access to resources like high-quality schools, safe neighborhoods, good jobs, and quality health care. In other words, racism affects health by shaping the SDOH. She noted, too, that racism occurs at three levels: internalized, personally mediated, and institutional (Jones, 2000). Internalized racism, she said, will be familiar to many Black people, because living in a place that devalues someone leads them to start devaluing themselves. She added that it is also internalized racism when a white person believes that because they are white they are supposed to already have resources, and therefore they vote against policies that might benefit them, such as the Patient Protection and Affordable Care Act (ACA) or Medicaid expansion, because they view them as "for Black people."

Personally mediated racism is the phenomenon that comes to mind for most people when they hear the term racism. It refers to an overt expression of racism, such as using a racial slur. While that does happen, Crear-Perry explained, it is not the overarching reason for poor maternal health outcomes. Rather, said Crear-Perry, the primary cause is institutional racism. She stated that this undergirds, for example, how states decide whether to expand Medicaid or not, and it is the reason that having health care coverage is tied to having a job. "Why is your employment tied to your health? Those are the structures that we have internalized and institutionalized to believe who is deserved of health and not," she said.

There is a long history of reproductive injustice in the United States. Experiments performed on Black female enslaved people paved the way for modern gynecology and led to the narrative that Black people did not feel pain. This idea, she said, is still deeply held today by medical students, residents, and faculty. "Clearly, medical students do not learn it from the air," said Crear-Perry. "They learn it from their presenters, from their faculty members, from their deans, from their presidents." Crear-Perry also contended that this

country's policies regarding infertility treatment, and specifically the failure of employer-based insurance to cover fertility treatments, is based in eugenics. Eugenics is a belief in stratified reproduction, which says that some people deserve to have children and others do not. While other high-income countries provide infertility treatment through public insurance, the attitude in this country is that it is only for the wealthy. "This idea of who is valuable and who should have children, and manipulating that through family planning and population control, must end," she stated.

Crear-Perry noted that Black birthing peoples' voices need to be sufficiently centered in the maternal care system and that it is important for their experiences to be validated and respected. This includes protecting their right to direct and be informed in their care. She emphasized the importance of health care providers stepping up to mitigate and address both implicit and explicit biases. She added that to address maternal mortality, it is paramount that "care originates from, and is defined by, Black women led organizations, practitioners, and community members."

To get an idea of what it would look like to have respectful maternal care in the United States, NBEC staff interviewed Black birthing people across the country for their ideas. Birthing people want accountability, empathy, and safety, which requires undoing the racism that devalues them. They want clinicians to trust them and to stop referring to them as noncompliant without acknowledging institutional racism. Crear-Perry wondered what would happen if a clinician were unable to write the word noncompliant in an electronic health record. Perhaps they would instead have to figure out what was happening in the lives of their patients, that they could address in order to meet their needs and ensure that they feel they deserve care, empathy, and safety. She noted that during the COVID-19 pandemic, the lack of transparency and information increased people's feelings that they did not deserve respectful care.

Crear-Perry then presented what she called the cycle of respectful care, which her team developed with colleagues at the American College of Obstetricians and Gynecologists (ACOG). At the core lies the care provider's decision to embrace the practitioner's oath, whether it is the Hippocratic Oath,

<sup>&</sup>lt;sup>11</sup> Implicit bias is defined as when individuals have attitudes toward people or associate stereotypes with them without their conscious knowledge of doing so. Explicit bias is the traditional conceptualization of bias, when individuals are aware of their prejudices and attitudes toward certain groups. Overt racism and racist comments are examples of explicit biases. See https://perception.org/research/implicit-bias (accessed August 19, 2021).

the Imhotep Oath (Pickett, 1992), or the Nightingale Oath. <sup>12</sup> From there, the first step is to get ready as an individual by unlearning the unhelpful and simply wrong ideas that one is exposed to about patients, and waking up to the problem of, in this case, disproportionate maternal mortality and morbidity caused by the SDOH and the effects of institutional racism.

The next steps in the cycle are to work with other providers, create change in the community, and then circle back to continue improving oneself. In Crear-Perry's case, she said that she is working on decolonizing herself, because as a Black person in the Americas, she is deeply colonized. It is important, she said, to unlearn so much of the incorrect history that is taught in the United States. As an example, she noted that while Abraham Lincoln is viewed as a kind and moral man and though he did condemn slavery, he also believed that Black people were broken, that they had served their purpose, and that they needed to go back to the places from which they came. "So if you are working on maternal health and believe that the people you are helping are broken and it is your job to save them, we do not need you in this work," said Crear-Perry. "We need you to know that we are not broken, that it is policies and cultural beliefs that have been trying to break us. We all want to be actively antiracist, and that means we have to see each other as all fully human and that we all are deserving of justice and joy."

#### Strategies to Reimagine and Disrupt the Root Causes of Poor Maternal Health Outcomes

Presented by Monica McLemore, University of California, San Francisco

To begin her remarks, Monica McLemore reminded the workshop that racism has been declared a public health crisis (Andrews, 2021). She emphasized that racism results in "prevalent and persistent structural flaws in the nation's structures," which have negative implications for health outcomes. These flaws lead to inequitable access to the SDOH, and manifest in outcomes

<sup>&</sup>lt;sup>12</sup> A modification of the traditional Hippocratic Oath, the Nightingale Oath was composed in 1893 to reflect the founder of modern nursing, Florence Nightingale. The text of the oath is as follows: "I solemnly pledge myself before God and in the presence of this assembly, to pass my life in purity and to practice my profession faithfully. I will abstain from whatever is deleterious and mischievous, and will not take or knowingly administer any harmful drug. I will do all in my power to maintain and elevate the standard of my profession, and will hold in confidence all personal matters committed to my keeping and all family affairs coming to my knowledge in the practice of my calling. With loyalty will I endeavor to aid the physician in his work, and devote myself to the welfare of those committed to my care." See https://nursing.vanderbilt.edu/news/florence-nightingale-pledge (accessed August 19, 2021).

such as the larger burden of COVID-19 incidence and mortality in Black and Latinx populations and the higher rates of violence and police brutality that Black, Indigenous, and other communities of color face. She noted, though, that if there is one thing the COVID-19 pandemic has taught her, it is that the system has so many flaws that it needs to be reimagined, and, more importantly, that the opportunity exists to do just that.

With that idea as the foundation for her remarks, McLemore went on to list what she views as the three root causes of poor health outcomes for birthing people of color: mistreatment and disrespectful care, reproductive injustice, and a lack of diversity in the health care workforce. She noted that in 2019, she wrote a piece for *Scientific American* titled "To Prevent Women from Dying in Childbirth, First Stop Blaming Them." In that article, she summarized existing knowledge about the root causes for maternal morbidity and mortality in the United States and carefully explained that many of these deaths were preventable, with symptom surveillance, early symptom recognition, and reporting being critical components of prevention.

Unfortunately, she said, disrespectful care and mistreatment during pregnancy and childbirth are widespread in the United States, and disproportionately impact birthing people of color. She and her collaborators have found, for example, that one in six birthing people report experiencing one or more types of mistreatment, including being shouted at, scolded, or threatened, being ignored, refused, or receiving no responses to requests for help (Vedam et al., 2019). Moreover, these experiences contribute to significant delays in providing care to pregnant-capable people. She also pointed out that patient mistreatment and clinician burnout are two sides of the same coin, as both are symptoms of inhumane workplaces. "Until we address that structural issue, we will continue to see the provision and receipt of disrespectful care," said McLemore. She stated that one consideration is that, for too long, birthing people have had limited options in how, where, and with whom they shepherd new humans into the world. She proposed that birth settings such as auxiliary and alternative maternity units should be bolstered (NASEM, 2020).

In her view, achieving health equity and addressing reproductive injustice is the scientific equivalent of evidence-based truth and reconciliation. In that respect, maternal morbidity and mortality are significant public health issues that highlight shameful health disparities that burden Black and Indigenous communities. She clarified that inequities in maternal morbidity and mortality are a symptom of the underlying problem, which is reproductive injustice in the United States (Davis, 2019b), because inequities in the reproductive health outcomes are not exclusive to the perinatal and postpartum periods.

<sup>&</sup>lt;sup>13</sup> See https://www.scientificamerican.com/article/to-prevent-women-from-dying-in-childbirth-first-stop-blaming-them (accessed August 14, 2021).

Looking across the reproductive spectrum of adoption, abortion, contraception, family planning, maternal-fetal medicine, reproductive endocrinology and infertility, and gynecologic oncology, Black and Indigenous individuals have poorer outcomes when compared to white pregnant-capable people (Eichelberger et al., 2016). Moreover, said McLemore, these observations of poor reproductive outcomes for Black and Indigenous individuals are important because the experiences of care that people have during their reproductive years have lifelong implications for if, when, how, and where they choose to access health care in the future.

As Crear-Perry discussed, disparities in the distribution of disease, illness, and wellness are not exclusively determined by the behavior of individuals, but rather are strongly influenced by the SDOH, which McLemore pointed out do not arise out of thin air. Crear-Perry says that addressing the SDOH requires structural approaches, given their central role in fueling reproductive injustice and how they are powered by institutional racism, class oppression, and gender discrimination and exploitation; or in other words, interventions that target individuals are insufficient to address structural problems.

For example, Crear-Perry says that research has shown that the burden of maternal morbidity and mortality is greater among Black birthing people, regardless of routine prenatal care, socioeconomic status, education, insurance types, and rates of preexisting clinical conditions. In addition, data from a recent study that examined the dual burden of severe maternal morbidity and preterm birth show that these combined clinical experiences have the potential to disrupt maternal role attainment, lactation and breastfeeding, the transition of families, and postpartum mental health (Lyndon et al., 2021). All of these have important life course implications for individuals. These data, said McLemore, highlight the limitations of relying exclusively on hospital-based birth data, because they represent only a single episode—birth—whereas pregnancy occurs over time and happens everywhere, not just in the hospital.

Given that disrespectful care, mistreatment, and poor reproductive health outcomes are occurring, McLemore said she believes in the importance of developing, deploying, and evaluating community-centered interventions. Her research, as well as that of many others, has described the health care—seeking behaviors and experiences of Black birthing people and Indigenous people across the reproductive spectrum, including by investigations into structural racism and strategies to improve maternal health services provision, patient satisfaction, and information and power exchange during health care encounters. In her view, addressing the SDOH that impact poor outcomes should focus more on community-sensitive outcomes; for example, rather than only focusing on the outcome of simply surviving birth, there should also be an emphasis on outcomes in the fourth trimester such as maternal role attainment, lactation and breastfeeding, family transitions, and postpartum mental health.

One hypothesis, generated from previous community-engaged research that McLemore's team has conducted, is that access to racially concordant and culturally relevant teams—case managers, doulas, midwives, nurses, nutritionists, physicians, and social workers—are essential components that work synergistically to improve experiences of care and trust in health systems. Racial discordance between clinical providers, clinician scholars, and communities have important and powerful ramifications for care (Hardeman et al., 2019, 2020; Karbeah et al., 2019; Kozhimannil et al., 2017). Interpersonal processes of care, including social concordance and communication, are significant aspects of quality care. Nonetheless, McLemore contends that these important findings have not spawned effective, novel, or sustainable interventions.

McLemore also noted that recent research that evaluated different models of care specific to the inclusion of a racial equity lens to curricular development and clinical care provision has shown that cultural and racial concordance are essential components to improving experiences of care across the reproductive spectrum, but especially for pregnancy-related care. A recent qualitative study identified four distinct themes that Black and Indigenous birth workers center on when providing racially concordant care (Karbeah et al., 2019). First, they call for clinicians to acknowledge how patients' cultural identities impact different aspects of the clinical encounter. Second, it is essential at both the interpersonal and institutional level to commit to achieving racial justice. The third and fourth themes were "agency and cultural humility," and "the reciprocal nature of the clinician–patient relationship" (Karbeah et al., 2019).

McLemore said that an additional example of reproductive injustice is the segregation that is rampant in the workforce for preventive health services. She pointed to data from 2015 showing that only 65.6 percent of the U.S. population is white, but 83.2 percent of licensed nurses and 90 percent of certified nurse midwives are white (Zangaro et al., 2018). While the physician community is more diverse at 49 percent white, only 4 percent of physicians are Black or African American, 4.4 percent are Hispanic, and 0.4 percent are American Indian or Alaska Native. Meanwhile, 93 percent of licensed nurses or certified midwives are women but only 34 percent of physicians are women, and while there are more Black women physicians than men—54.7 percent compared to 45.3 percent—in all other racial and ethnic groups there are more men physicians than women physicians (AAMC, 2017; Sullivan Commission on Diversity in the Healthcare Workforce, 2004).

There have been attempts to diversify the clinical health care workforce using incentive and pipeline programs, but these programs have had mixed results. Fortunately, said McLemore, these programs have shown that people of color in the health professions are more likely to serve minority populations, and that health care providers who are people of color are more likely to work with publicly insured and minority populations. It has also been shown,

she said, that programs that specifically develop Black and Indigenous health care providers to ensure an adequate workforce in underresourced settings are as successful as programs that provide financial incentives to any health care provider who serves minority populations and historically excluded communities (Wilbur et al., 2020).

In closing, McLemore said there is a unique opportunity today to curate a different conversation about the data that are necessary to improve health outcomes and to achieve health equity. Doing so, she said, requires disrupting stigma, shame, judgment, and blame narratives that are grounded in gender oppression and patriarchy, white supremacy, and misogynoir (a distinct form of racist misogyny experienced by Black women, as coined by Dr. Moya Bailey and described by Brownsyne Tucker Edmonds in a later presentation; Bailey, 2021). She also highlighted the need for partnership across the spectrum of disciplines who serve birthing people and pregnant-capable people. Finally, she urged, the nation should move past pontificating about poorer outcomes and instead construct the care and policies that are required to achieve improved outcomes. She called for a robust social safety net that includes paid family leave, expansion of insurance coverage, and improved access to services.

#### Indigenous Reproductive Justice

Presented by Marinah Farrell, Changing Women Initiative

In the final presentation of the panel, Marinah Farrell described the root causes of inequities in maternal health outcomes currently experienced by Indigenous peoples in the United States, and proposed potential approaches to begin addressing these injustices. She began her presentation by acknowledging and thanking the custodians of the land and their continuing connections to the land, water, and community, as well as the first people of the land of her roots and where she lives and works. She highlighted her identity as a first-generation immigrant and honored her ancestors and the knowledge they provided about traditional medicine and healing. She also acknowledged that the workshop was missing many voices today of Indigenous reproductive justice advocates, leaders, and midwives, who she praised for bringing healing to their communities and for being powerful influencers of change.

Finally, she acknowledged the pain and devastation that slavery and its legacy still cause to Africans and people of African origin. Farrell said,

I see slavery as a prayer that needs to be spoken aloud, because, truly, enslavement continues, though it is called other names, such as public health, incarceration, environmental devastation, family separation, poverty, systemic trauma, overrepresentation in the rates of violence against Indigenous and

Black peoples, and disparities in health outcomes, income levels, and education levels.

She stated that the government of the United States is responsible for the genocide, ethnic cleansing, and forced removal of Indigenous peoples, actions that were taken to acquire land and to control the bodies of Indigenous peoples. Farrell said,

This brought, to most Indigenous communities from sea to shining sea, unbearable suffering and death, violence, poverty, and illness. And yet the land has always and will always belong to the first peoples of this continent, just like there has been and will always be Indigenous midwives.

The poor maternal health outcomes experienced by Indigenous communities have their roots in this history, she said, and from the failure of the government to live up to its promises to provide health care in exchange for precious land. Those promises have withered into the underfunded Indian Health Service (IHS) that is often inaccessible for reasons of geography or financial considerations, and that is frequently staffed by non-Indigenous individuals who lack cultural comprehension or cultural compassion. Farrell said that, in fact, Indigenous birthing people, more than of any other race, report the highest level of mistreatment, another cause of maternal health outcomes.

Incomplete and flawed data that mask what are surely even greater disparities are another leading cause of the poor care Indigenous people in the United States receive, said Farrell. Poor and missing data render Indigenous people invisible, preventing much needed action to improve health care for Indigenous people in the United States. She noted that demographic definitions, which do not speak to the culture of Indigenous peoples, can erase them. Indeed, sometimes Farrell said that Indigenous individuals are forced to erase themselves, because there is no definition that feels safe to claim; they may see anonymity as preferable to mistreatment.

Borders can also restrict access to health care for Indigenous people, said Farrell, because of state or federal laws or restrictions on local health care plans and insurance. As an example, she shared a story of a recent birth attended by a Diné<sup>14</sup> midwife, which occurred on Diné land in Arizona. Farrell explained that the midwife could not file the birth certificate because she was licensed in New Mexico, not Arizona. As a result, Farrell, a non-Diné person, had to attend the birth to meet the state and federal requirements imposed on this Native midwife. "When we remember that every tribe is sovereign, a nation

<sup>&</sup>lt;sup>14</sup> Diné is the preferred name for the Navajo people, meaning "The People" or "Children of the Holy People." See http://navajopeople.org (accessed August 19, 2021).

unto itself, then we remember that the families and the babies should also be entitled to birth in and among their own, in their own way, and under their own regulations," she explained. She noted that this is not a rare occurrence and, in some cases, there are national borders involved, as is the case with the Pascua Yaqui tribe of southern Arizona and northern Mexico. This division causes a loss of language, ceremony, and community that leads to further illness and suffering. "The uniqueness and beauty of the many individual Indigenous nations in our country must be deeply appreciated, particularly when we are thinking about the delivery of health care," said Farrell.

There are many Indigenous midwives in the Americas, but almost none in the United States, said Farrell. She explained that in the United States, Indigenous and Black midwives have been attacked and blamed for what are actually systemic health care issues that endanger lives. These attacks also belittle the culture of the Indigenous person, their beliefs, and their ceremonies. The subjugation of Indigenous practices and peoples, such as the midwife, was and often still is legally sanctioned and championed by the U.S. system of health care, said Farrell.

In her view, the disappearance of Indigenous midwives is a major cause of poor maternal health among Indigenous people. "In this colonized lifestyle, the traditional ways of birth have been forgotten," said Farrell. "What seems to be in the mind of many Indigenous families are the separations, the abusive ways Indigenous peoples are treated in hospital, the inaccessibility of hospitals or even health centers, the failures of [the] Indian Health Service when it comes to providing reproductive health care and abortion care."

Farrell proposed a few practical solutions to this problem. First would be to support the traditional or professional midwife in this country as an autonomous provider. Second, the government should ensure that IHS has adequate funding and is made accountable to honor full-spectrum reproductive and pregnancy care for the Indigenous community they serve, staffed with a workforce of Native and Indigenous peoples from the same community. Third, medical systems must offer reconciliation and admit to the abuses that have happened and continue to happen, including being inaccessible to Indigenous peoples. She pointed out that while COVID-19 was devastating to Indigenous peoples, the data still do not reflect the reality of how the underfunding of health care for Native peoples is a persistent and critical issue. The federal government could resolve this issue with a more realistic IHS budget that at least matches the average expense of basic health care for all members of tribal societies.

It is her hope that legislators will fund land reclamation, knowing that tribal communities disproportionately lack access to clean and safe drinking water, sanitation, and affordable and safe housing. Road conditions in tribal communities are often poor, and during the pandemic, those who relied on air and water transport were left stranded and without access to care, supplies,

personal protective equipment, and more, she said. Even as telehealth was made available, another unforeseen obstacle was the digital divide, which left many communities unable to access prenatal or postpartum care. "The solution is that we must work on filling the gaps immediately with a workforce of Indigenous, community-based birth workers and bring back our midwives so that every tribal nation can meet the unique need of every Indigenous person, baby, and elder living within or outside of a tribal community," said Farrell.

On a final note, she said her organization is working to reclaim midwifery and community birth, and is doing it through a lens of trauma-informed care. <sup>15</sup> She and her colleagues are also engaging in policy work to improve Indigenous maternal health.

## EXAMINING THE BURDEN OF MATERNAL MORBIDITY AND MORTALITY

The second session featured three speakers who provided an overview of the burden that poor maternal health outcomes—including maternal morbidity and mortality—have on the lives of individuals, families, and society. The speakers were Rear Admiral (retired) Wanda Barfield (CDC), Laurie Zephyrin (The Commonwealth Fund), and Abigail Echo-Hawk (Seattle Indian Health Board and Urban Indian Health Institute). Following the three presentations, Brownsyne Tucker Edmonds moderated a discussion among the panelists.

#### Measuring Maternal Mortality

Presented by Rear Admiral (retired) Wanda Barfield, Centers for Disease Control and Prevention

"Because maternal mortality is a multifactorial problem, we need to think about robust and more detailed data to better understand and prevent these deaths," said Wanda Barfield. In the United States, three terms are used for measuring maternal mortality. These come from the 10th revision of WHO's *International Classification of Diseases* (2004):

 Maternal death, which is the death of a birthing person while pregnant or within 42 days of the termination of pregnancy, regardless

<sup>&</sup>lt;sup>15</sup> Trauma-informed care is an approach that recognizes and responds to the signs, symptoms, and risks of trauma to better support the health needs of patients who have experienced adverse childhood experiences and toxic stress. The goal is that any care provided takes into account the person's gender identity and racial/ethnic cultural backgrounds and experiences. See https://www.acesaware.org/ace-fundamentals/principles-of-trauma-informed-care (accessed August 19, 2021).

- of the duration or site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental causes.
- Pregnancy-related death, which refers to death during or within 1
  year of pregnancy, from a pregnancy complication, a chain of events
  initiated by pregnancy, or from the aggravation of an unrelated
  condition by the physiologic effects of pregnancy. Similar to maternal
  death, these deaths are specifically related to pregnancy, but the time
  period is extended out to 1 year after the end of pregnancy.
- Pregnancy-associated death, which is death during or within 1 year of pregnancy, regardless of the cause.

Barfield noted that there are three important sources of data on maternal mortality. The National Vital Statistics System (NVSS), a surveillance system led by the National Center for Health Statistics (NCHS), reports maternal deaths, which are defined as those that occur during pregnancy or within 42 days of delivery or termination of pregnancy (WHO, 2004). The Pregnancy Mortality Surveillance System (PMSS) uses death certificates and linked birth or fetal death certificates and defines pregnancy-related death as occurring during pregnancy or within 1 year after pregnancy. PMSS has been run by CDC's Division of Reproductive Health since 1987, and it also provides information on the overall pregnancy-related mortality rates, rates by state and by race/ethnicity, and the timing of death and relationship to pregnancy.

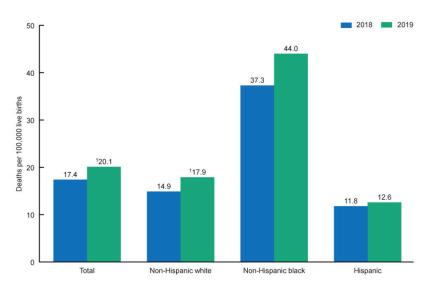
PMSS does not provide the entire picture, however, because maternal mortality is a multifactorial problem, said Barfield. That is where MMRCs are important. MMRCs, she explained, are part of a multidisciplinary process where a committee at the state or city level identifies and reviews pregnancy-associated deaths that occurred during pregnancy or within 1 year, regardless of the cause. MMRCs have access to multiple sources of information that provide a deeper understanding of the circumstances surrounding each death. A third data source is the Maternal Mortality Review Information Application (MMRIA). This is a CDC data system that provides a common data language for MMRCs. MMRIA facilitates documentation of a wide range of data over the life and death of a person. Over time, CDC has added components to MMRIA, based on feedback from state users, that have facilitated enhanced data collection on maternal substance use and SDOH, for example. Altogether, these data sources ensure that a review committee can develop strong preventive recommendations.

Overall, these data sources show that each year, some 700 women in the United States die during or within 1 year of the end of pregnancy as a result of pregnancy or delivery complications, including during pregnancy, labor/delivery, or up to 1 year after the end of pregnancy. American Indian and

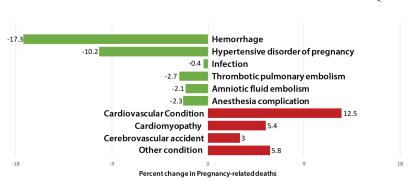
Alaska Native women are two times more likely to die than white women, and Black women are three times more likely to die than white women. The data also suggest that about two-thirds of these deaths may be preventable, said Barfield. The birthing people who die during pregnancy or their postpartum period are just the tip of the iceberg, however. "We know that there are many women, about 50,000, who suffer from severe complications of pregnancy each year, and even more have chronic conditions during pregnancy that give us a window to their future health," said Barfield.

NCHS's release of 2019 mortality data from the NVSS found a statistically significant increase in maternal mortality data over the previous year, she noted, rising from 17.4 deaths per 100,000 in 2018 to 20.1 deaths per 100,000 in 2019 (see Figure 2). Data from the PMSS, which provides a longer look postpartum, show that pregnancy-related mortality had not improved between 1999 and 2017.

PMSS tracks 10 causes of pregnancy-related deaths, and while some of these measures had improved between 1987 and 2013, some have gotten worse (see Figure 3). For example, deaths from hemorrhage and hypertensive disorder of pregnancy decreased during that period, while deaths from cardiovascular disease and other conditions have increased. Peterson et al. (2019) also found that "cardiomyopathy, thrombotic pulmonary embolism, and hypertensive disorders of pregnancy contributed to a significantly higher proportion of pregnancy-related deaths among Black women than among



**FIGURE 2** Maternal mortality data, 2018 and 2019. SOURCES: Workshop presentation by Barfield on June 7, 2021; NCHS.



**FIGURE 3** Causes of pregnancy-related deaths between 1987 and 2013. SOURCES: Workshop presentation by Barfield on June 7, 2021; PMSS.

white women." Furthermore, pregnancy-related deaths associated with hemorrhage and hypertensive disorders occurred more often among American Indian and Alaska Native women compared with white women (Petersen et al., 2019; see Figure 4). "We need to consider these differences in equitable efforts to reduce maternal mortality," said Barfield.

The PMSS data analyzed by Peterson et al. (2019) also confirm that racial and ethnic disparities occur at all education levels, as described by the first panel: the pregnancy-related mortality ratio (PRMR) among Black women with a completed college education or higher was 1.6 times that of white women with less than a high school diploma. Additionally, among women with a college education or higher, the PRMR for Black women was 5.2 times higher than for white women with the same education level. The data also highlighted that even when a state's overall PRMR was low, or even when considering a group with higher levels of education, there were still disparities hidden within those rates. These findings, according to Peterson et al. (2019), highlight that the inequity in "pregnancy-related death for Black and American Indian/Alaska Native women is a complex national problem."

NVSS and PMSS are limited by the availability of vital statistics, but MMRCs can provide more detailed information as a means of better understanding the causes of pregnancy-related deaths. These data show that mental health conditions are also a leading cause of pregnancy-related deaths (see Figure 5). When reviewing deaths out to 1 year, these data capture most of the cardiomyopathy deaths—a leading cause of death in the late postpartum period—which would be missed over a shorter time (Davis et al., 2019).

In terms of the timing of death related to pregnancy, the PMSS data show that 31 percent of the deaths occur during pregnancy. Another 36 percent, said Barfield, occur during delivery and up to 1 week after delivery, and 33 percent occur in the period between 1 week and 1 year after delivery.

CDC is supporting efforts to investigate the effects of COVID-19 on

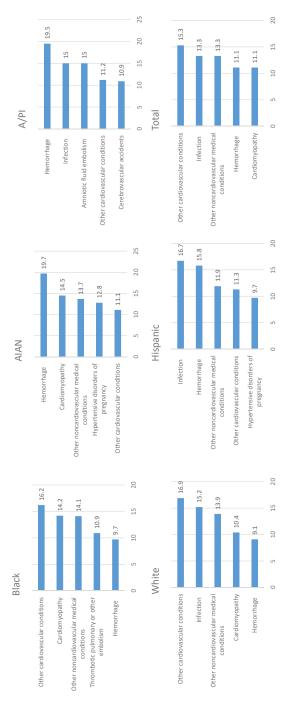
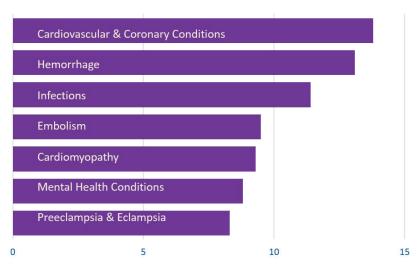


FIGURE 4 Cause-specific, pregnancy-related mortality, by race/ethnicity, 2007–2016. NOTE: A/PI = Asian and Pacific Islander; AIAN = American Indian and Alaska Native. SOURCES: Workshop presentation by Barfield on June 7, 2021; Petersen et al., 2019.



**FIGURE 5** Leading cause of pregnancy deaths from MMRC data. SOURCES: Workshop presentation by Barfield on June 7, 2021; Davis et al., 2019.

pregnant people and infants. Current data show that although the overall risk for severe illness from COVID-19 is low, pregnant people and recently pregnant people are at increased risk when compared to people who are not pregnant. Barfield explained that there are physiologic changes in pregnancy that could increase the risk of severe illness, including and not limited to increased heart rate and oxygen consumption, decreased lung capacity, and the shift away from cell-mediated immunity (Ramsey and Ramin, 2001). Severe disease in pregnant people has been associated with other viral respiratory infections (Mosby et al., 2011). The data also show that pregnant people with COVID-19 have an increased risk for adverse pregnancy outcomes such as preterm birth (Galang et al., 2020) and that Hispanic and non-Hispanic Black pregnant people appear to be disproportionately affected by COVID-19 infection during pregnancy. In fact, Hispanic pregnant people of any race experienced both a disproportionately higher risk of SARS-CoV-2 infection and a higher risk of death compared with nonpregnant Hispanic people (Zambrano et al., 2020).

Barfield concluded her talk with a brief summary of what actions CDC is taking to address inequities and improve maternal and infant morbidity and mortality. CDC's Maternal and Child Health Epidemiology Program, for example, works on "building capacity at state, local, and tribal levels and to use and apply sound epidemiologic research and scientific information to

maternal and child health programs and policies." <sup>16</sup> Currently, there are 13 CDC maternal and child health epidemiologists working directly in states. CDC is also working to better understand the impact of the SDOH by collecting more robust data, and then tying those data to action.

In addition, CDC funds the effort of Perinatal Quality Collaboratives (PQCs), which are state-based initiatives that aim to improve the quality of care that mothers and babies receive. CDC is also working with the National Network of PQCs to expand the reach of lessons learned on a national scale. The collaboratives, explained Barfield, help create quality, standardized care by translating the information that MMRCs develop into policy and practice changes. CDC's Levels of Care Assessment Tool (LOCATe) program helps states and other jurisdictions address systems of risk-appropriate care in their regions, because it enables them to show the capabilities and staffing services within maternal and neonatal care among delivery facilities.

### Factors Contributing to Maternal Morbidity and Mortality

Presented by Laurie Zephyrin, The Commonwealth Fund

Until around 1998, said Laurie Zephyrin, maternal mortality had been gradually decreasing, before beginning to rise again. During the decades when maternal mortality fell and as birthing people started to experience healthier living conditions and better maternity services, there was a great deal of focus on improving surgical procedures and access to antibiotics, as well as an additional focus on improving maternity services within hospitals. "This focus on improving maternity care in hospitals has had some consequences by not providing the focus on the importance of community-based care, and also overlooking persistent racial disparities," said Zephyrin.

As other speakers had noted, Black birthing people have been more likely to die than white birthing people, a situation that has existed for over a century, and, as highlighted by several speakers during the workshop, education is not protective. In fact, said Zephyrin, education exacerbates instead of mitigates Black and white differences in maternal health outcomes, with five times as many Black mothers with a college education dying compared to white mothers with a college education (The Commonwealth Fund, 2020).

Zephyrin said that, while the existing data show that the chance of dying in childbirth is twice as high in some states than in others, this picture is clouded by the fact that many states do not collect or report data on maternal mortality and morbidity. She expects the work that Barfield and her colleagues

<sup>&</sup>lt;sup>16</sup> See https://www.cdc.gov/reproductivehealth/mchepi/index.htm (accessed August 18, 2021) for more information.

are doing will address this problem, and those data will be critical to understanding differences among states, and to directing policy action at the state and federal levels to mitigate those inequities.

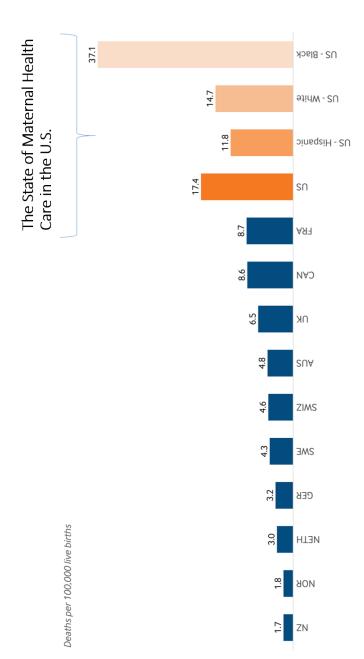
The substantial racial and ethnic disparities in the incidence of maternal morbidity are important, said Zephyrin, especially given that maternal morbidity has significant effects on the quality of life for parents and their children. Maternal morbidity can result in disability, precipitate poorer health, and have adverse socioeconomic effects. "There are additional data and interventions needed to help guide policy makers, community leaders, and health system leaders to develop the business case to better understand the importance of maternal morbidity and the impact maternal morbidity has on people's lives and their health and social well-being," said Zephyrin.

As Barfield explained, maternal mortality falls into three buckets: during pregnancy, around the time of delivery, and up to 1 year after giving birth, with the latter bucket accounting for a little more than half of maternal mortality. These data show the critical importance of, when thinking about interventions, not just focusing on the delivery or birthing aspects or prenatal aspects, but continuing to focus help through the first year after giving birth. In particular, Zephyrin called out the need to address the SDOH, and the structural racism that drives those social determinants, during that postnatal period so that new mothers and their infants have the ability to be healthy and thrive without the burden of morbidity.

When the performance of the U.S. health care system is compared to that of similar countries, as Crear-Perry showed, the picture is not a flattering one. Zephyrin and her colleagues looked at 10 other countries with at least 300,000 births and a gross domestic product of \$40,000 per capita or more. The United States, she said, ranked last overall in preventable deaths, even without considering the prominent racial differences in maternal health outcomes that exist in the United States (Tikkanen et al., 2020; see Figure 6). "Even though the United States spends more on health care than anywhere in the world, it has the highest rates of these preventable deaths, which is really shocking," said Zephyrin.

As Farrell noted, the supply of midwives in the United States is limited, as is the supply of obstetricians. In fact, Zephyrin and her colleagues found, among high-income countries, only Canada has a smaller supply of maternal health care providers per 1,000 live births (Tikkanen et al., 2020). In many European countries, midwives are at the center of delivering maternity care, whereas in the United States, midwifery services may not even be covered by insurance or available in some regions of the country, particularly if the desire is to have a culturally concordant midwifery provider, said Zephyrin.

One social determinant of health that affects the postnatal period is the availability of paid maternity leave, and of the 10 high-income countries,



NOTE: AUS = Australia; CAN = Canada; FRA = France; GER = Germany; NETH = The Netherlands; NZ = New Zealand; NOR = Norway; SWE FIGURE 6 The state of maternal health care in the United States relative to other high-income countries. SOURCES: Workshop presentation by Zephyrin on June 7, 2021; Tikkanen et al., 2020. = Sweden; SWIZ = Switzerland; UK = United Kingdom; US = United States.

Zephyrin and colleagues found that the United States is the only one not to guarantee any weeks of paid maternity leave. Moreover, the United States is the only 1 of the 10 countries in which national insurance does not cover postpartum home visits, with coverage varying by state Medicaid programs and by individual insurer (Tikkanen et al., 2020). Medicaid, Zephyrin pointed out, pays for about half of all U.S. deliveries. In those states that do cover postpartum home visits, that benefit only extends for up to 60 days. <sup>17</sup>

In thinking about the policy implications of these data, Zephyrin said, Medicaid reform in particular has a significant opportunity to impact birthing people's health outcomes, including maternal morbidity and mortality. "As we think about maternal mortality and these drivers, it is important as we think about policy solutions to address opportunities in Medicaid to be able to expand coverage and services across all states," she said. For example, a recent analysis found that about one-third of uninsured new mothers would be eligible for coverage with a 12-month postpartum Medicaid extension.

At the same time, she added, it is also important to think more broadly about how to address the inequities and failures in the nation's overall maternal health system. "We have to think of the importance of comprehensive primary health care and designing gender-specific primary health care, as well as primary health care integrated into coverage, so that birthing people have access to care before and beyond pregnancy," said Zephyrin. "We cannot separate maternal mortality and morbidity from the systems in which they arise."

Also important, said Zephyrin, is the need to address unequal treatment that women and birthing people of color receive and their unequal experiences in the health system, such as the disrespect they endure and the lack of autonomy they are granted over their care. In short, addressing unequal outcomes in morbidity and mortality requires addressing this unequal treatment and unequal experiences. This need has been laid bare by the conjunction of the maternal health crisis and the COVID-19 pandemic that has increased disparities and even erased the life expectancy gains achieved in previous years for Black adults relative to white adults.

Turning to solutions, Zephyrin said there are evidence-based, community-based models that are proven to improve maternal morbidity and mortality. For example, birthing people at high risk for adverse birth outcomes receiving care from doulas, compared with those not receiving care from doulas, are two times less likely to experience a birth complication, four times less likely to have a low-birthweight baby, more likely to breastfeed, and more likely to be satisfied with their care (Zephyrin et al., 2021). Similarly,

<sup>&</sup>lt;sup>17</sup> The District of Columbia and 38 states have benefits beyond the 60-day limit. Non-Medicaid expansion states are more likely to have mothers who run out of care at the 60-day limit (Ranji et al., 2021).

midwifery-led maternity care results in higher rates of vaginal delivery (as opposed to cesarean section), significantly lower rates of preterm births, and lower rates of low-birthweight infants compared with other maternity models (Zephyrin et al., 2021).

Zephyrin also highlighted group prenatal care models<sup>18</sup> and pregnancy medical home models<sup>19</sup> as innovative interventions. Group prenatal care models have been found to achieve reduced rates of preterm births by as much as 41 percent, and to reduce rates of neonatal intensive care unit (NICU) admissions, low birthweight, and emergency department visits during pregnancy (Zephyrin et al., 2021). They also increase breastfeeding, patient and physician satisfaction, and parental knowledge regarding childbirth and child rearing (Zephyrin et al., 2021). Zephyrin says that pilot programs of the pregnancy medical home model in a few states have reduced emergency department visits, premature births, cesarean section births, and low-birthweight rates, while increasing the likelihood of attending a postpartum visit (Zephyrin et al., 2021).

Zephyrin concluded her remarks by noting that the COVID-19 pandemic has highlighted the need for high-value care that addresses the effect of structural racism in U.S. society, and how quickly the nation can move to implement changes. "So as work moves forward to invest in a diverse perinatal workforce, strengthening and supporting birthing centers, or even work around extending postpartum Medicaid coverage to 1 year, it is even more urgent now that we make these investments," said Zephyrin.

### The Burden of Maternal Morbidity and Mortality Among American Indian and Alaska Natives

Presented by Abigail Echo-Hawk, Seattle Indian Health Board and Urban Indian Health Institute

After noting that Native people have been storytellers for many generations, and that it is part of their scientific methodology, Abigail Echo-Hawk started her presentation with a story about an 18-year-old woman who found herself pregnant in a large city. Having never been outside of the IHS system

<sup>&</sup>lt;sup>18</sup> Group prenatal care models are those in which individuals receive both standard, individual prenatal care from a health provider, and also attend group sessions with other pregnant patients in which a health care provider facilitates discussions on relevant prenatal health topics (Zephyrin et al., 2021).

<sup>&</sup>lt;sup>19</sup> Pregnancy medical homes are a model of comprehensive perinatal health care, where services such as prenatal care, care coordination, and risk screening are co-located. They may provide prenatal care beginning earlier in the first trimester, have expanded office hours to increase accessibility, and emphasize patient decision making. Under this model, care teams may be financially incentivized to meet patient care goals (Zephyrin et al., 2021).

before, she accessed a large hospital in a large urban area. At her first prenatal visit, the medical assistant, seeing that the girl was Native American, began questioning her about her drinking habits and would not believe that she did not drink, nor that she did not use drugs. As a result of this outwardly racist visit, this young woman did not return to receive prenatal care until she was well into the second trimester of her pregnancy.

This is not an unusual story, said Echo-Hawk; 28 percent of American Indians and Alaska Natives in urban areas typically do not initiate prenatal care until the second trimester, which research has shown increases the risk of both infant and maternal death. Echo-Hawk said that what this points to is that the system of medical care in the United States has been structured in a way that inhibits the ability of American Indians and Alaska Natives to receive the care they should.

Echo-Hawk echoed Marinah Farrell's point that current data collection systems inhibit proper references to American Indian and Native American populations. This is partly due to the small size of the population, which sometimes results in erasure during analysis. She called on those who work in epidemiology and on vital statistics to ask why they do not reflect the experiences of American Indigenous people and to start using accepted methods of representing small populations in epidemiologic data. One such strategy is to aggregate multiple years of data to generate a large enough sample size for reporting outcomes, of both morbidity and mortality, so as to not run afoul of privacy issues. Often, she said, when she works with states and counties, they simply do not do that work because it takes extra time. She said, "Think about us as a small population as a direct result of genocide. We should be prioritized for the time and given the resources to calculate the data correctly, in order to truly understand what is happening to our population, so that we are not complicit in the ongoing attempted erasure and genocide of Indigenous peoples." She noted that there is rampant racial misclassification of American Indians and Alaska Natives in data. On average, between 20 to 40 percent of the data in vital statistics involve racial misclassification. Because those data grossly underestimate what is happening to American Indians and Alaska Natives, they directly inhibit the ability to understand what is happening with the population.

She also noted that some American Indians and Alaska Natives will, if they can, pass for white because they know they will receive better services that way, which again, leads to misclassification and undercounting. "So some of our folks are intentionally not recognizing themselves in your data systems as American Indian and Alaska Native because they are too afraid of you," said Echo-Hawk. "That is not a problem of them. That is a problem of us, in this field, so how do we shift our systems to ensure that we are properly treating

our people with the dignity that they deserve, because right now, that dignity does not exist, but it is not something that is unachievable." In fact, her website<sup>20</sup> lists specific ways to improve the racial classification of American Indians and Alaska Natives that include respecting the tribal entities from which the data come.

Echo-Hawk explained that IHS is the medical care provider for about one-third of American Indians and Alaska Natives living in the United States, and reiterated Farrell's explanation that its creation was a direct result of treaty rights. Unfortunately, she said, the IHS continues to be chronically underfunded, and in fact, generally operates at about 38 percent of funding for the overall need. "As a direct result, we do not get the resources and services that we need, and it directly impacts the entire life stages of every one of our individuals who birth and their ability to access the resources they need from the medical systems," she said. In addition, American Indian and Alaska Native people cannot access many other systems that would help to address the SDOH.

Her team has collected data on maternal mortality in urban areas where there are IHS facilities and found that at a national level, American Indian and Alaska Native birthing people were 4.2 times more likely to die than non-Hispanic whites as a result of pregnancy-related complications. She recounted how she released these data on Twitter when she noticed that CDC had not included data for American Indian and Native American people in one of its data releases. She noted that this finding was generated by a tiny nonprofit organization.

One result of the release of her team's data on Twitter was that a reporter who was working on a story about Native American maternal mortality contacted her, and Echo-Hawk put her in touch with several pregnant women who were experiencing a large number of issues related to the SDOH. In the course of that story, one woman, Stephanie Snooks, and her twin babies died. "This is not an uncommon experience and is way too normal," said Echo-Hawk. Over the past 12 months, she has known three babies and one mother who have died. However, when she tried to publish a paper on health disparities among American Indian and Alaska Native people, CDC would not clear it for publication until her team took out a sentence from a Government Accountability Office report that mentioned sterilizations of Native birthing people, deeming it "inflammatory." A recent review found that among the top four medical journals in the world, fewer than 1 percent of peer-reviewed articles actually said the word racism. Moreover, out of that

<sup>&</sup>lt;sup>20</sup> See www.uihi.org (accessed August 18, 2021).

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less than 1 percent that said racism, 90 percent were opinion pieces, rather than empirical research.

To Echo-Hawk, this is yet another demonstration of the structural racism that exists and that has to be addressed, because it directly inhibits the ability to provide the proper care and address the SDOH. "Until we address inwardly the research and science field and the research enterprise, we will not make the changes we are attempting to do," she said, "because I will publish every single inflammatory paper I possibly can if it saves one more woman like Stephanie Snook."

#### Discussion

The first question for the panel came from an audience member, who asked Barfield if the data on maternal mortality also include statistics on abortion morbidity and mortality. The answer, said Barfield, is yes, the data include deaths occurring during any condition related to pregnancy. She noted that deaths associated with abortion are rare. She also said that the data on maternal mortality are largely comprehensive, nationally, in terms of the number of pregnancies captured. She noted that there is one potential gap: There may be instances in which a death occurs so early in pregnancy that the death is not linked to a birth event, which means it may be missed. She commented that this is a deficit that needs to be addressed.

Another audience member asked Barfield if PMSS distinguished between deaths that are associated and those that are not associated with pregnancy, to which she said that PMSS focuses on deaths that are related to pregnancy. However, she added, MMRCs, depending on the jurisdiction, can look at pregnancy-associated deaths, which include all deaths within 1 year after delivery, as well as pregnancy-related deaths. She also noted in response to another question that CDC does have information about the timing of when deaths occurred related to pregnancy.

Another asked what specific interventions the panelists would suggest that would mitigate system challenges and minimize the equity gap. Echo-Hawk stated that she would advocate for ensuring the availability of culturally based, community-specific resources and services. For example, the use of cradle boards for a newborn is a cultural practice among American Indians and Alaska Natives. This practice was discouraged and, as Echo-Hawk explained, "taken away" from these communities. In actuality, cradle boards meet every recommendation of the American Academy of Pediatrics for keeping babies safe when they sleep during their first year. She referred to the use of cradle boards as a culturally based practice that medical science is just catching up to, and argued that it is an example of what might be seen when investing in

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community-based solutions and when policy is driven by community-based solutions. Barfield agreed with Echo-Hawk regarding the need to look at these types of solutions to address the systems issues that affect maternal health overall. She noted that this is especially important in light of the fact that the majority of deaths are occurring in the later postpartum period.

### **BIRTHING EXPERIENCES IN CARE SETTINGS**

The workshop's third session featured four presentations on the experiences that birthing people have in care settings and how those experiences contribute to maternal health outcomes. The four speakers were Karen A. Scott (University of California, San Francisco, School of Medicine), Saraswathi Vedam (The University of British Columbia and Birth Place Lab), Brownsyne Tucker Edmonds (Indiana University School of Medicine), and Carolyn Sufrin (Johns Hopkins University).

# Prioritizing Patient Narratives and Community Wisdom in Quality Improvement and Implementation Science

Presented by Karen A. Scott, University of California, San Francisco, School of Medicine

Karen Scott's vision is to achieve a place of promise and potential that she called SACRED Birth. She describes this vision as "a radical attitude toward human births, specifically Blackness, Black bodies, and Black births, that regards all birth activities as fundamentally normal, healthy, spiritual, familial, magical, transformative, erotic, communal, emancipatory, and power-activating." SACRED Birth, said Scott, encourages "diverse and inclusive birth pleasure, practices, care, spaces, options, partners, communities, and experiences." She added that the SACRED Birth movement advocates for "safer, respectful, dignified, high-quality 'participatory' birth care, conditions, experiences, and outcomes, and improved workforce diversification, development, sustainability, and restoration of Black midwifery care and Black doula support models."

In the spirit of transparency, Scott shared four truths to demonstrate the beliefs and feelings amplified through the SACRED Birth movement for Black people:

- "We believe, trust, value, and adore Black people, women, and mothers.
- Black people, women, and mothers are worthy.

- We protect, prioritize, cite, and amplify Black women's and people's voices, intellectual thoughts, lived experiences, and political activism.
- We activate and advance the power and potential, not pathology, of Black people, women, and mothers and our given and chosen kin."

She contends that despite the establishment of PQCs,<sup>21</sup> advances in reproductive technology, and social protections (such as higher education), hospitals do not keep Black birthing people safe. Rather, a hospital's primary drivers, she said, include a lack of ethical boundaries, the perpetuation of white leadership, and a hierarchy of knowledge construction that is grounded in anti-Black and misogynistic ideologies and practices.

In addition, hospitals support ideas that fail to illuminate the oppression and resilience of Black women's and people's lived experiences. This is due to a lack of understanding the historical context and a misplaced culture of scientific rigor. By failing to reimagine quality improvement, ethics, leadership, knowledge, and science, hospitals miss opportunities to name misogynoir (Bailey, 2021), rather than race or gender alone, as the main driver for the presence and exacerbation of maternal prenatal inequities.

Scott said,

We must speak with transparency about the problem through a structural analysis of power, privilege, positionality, policies, people, and potential. Without truth, transparency, and trust, we fail to transform health service provision, training, and evaluation through dignified and equitable community partnerships and participation. Without community participation and partnership, we continue to weaponize race against Black women's interests, humanity, and liberation during hospitalization for birth.

Despite evidence to the contrary, said Scott, construction and dissemination of knowledge continues to reproduce and reinforce disturbing narratives that Black bodies are sub-humans, that Black lives are unworthy, and that Black mothers and people are to blame for disproportionate adverse birth outcomes. These misconceptions, she added, are then disseminated through many disciplines, including quality improvement and implementation science in the form of problematic stereotypes, scripts, and stories. These social and clinical norms then invade and infect interactions, communications, counseling, decision making, and dissemination, as well as documentation in patient handoffs and electronic health records.

<sup>&</sup>lt;sup>21</sup> PQCs are state or multistate networks of teams working to improve the quality of care for mothers and babies. PQC team members identify health care processes to be improved and then use the best available methods to make these changes as quickly as possible. See https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pqc.htm (accessed August 18, 2021).

In a recent paper, Scott explained how the spread of racism and perinatal inequity are compounded by the "controlling, constraining, and censoring" of Black women's voices and intellectual thoughts (Scott, 2021a). She also contended that there is a lack of accountability for these actions. "The problem with perinatal quality improvement innovation and transformation is the hypervisibility of Black women as victims and the structural exclusion and erasure of Black women as patient, community, and content experts," said Scott. Most perinatal quality improvement leaders and data scientists, she added, "lack nuanced knowledge and insight" into the various ways that power relations, differentials, and dynamics contribute to inequities in quality and safety (Scott, 2021a).

Perinatal quality improvement epistemology, which currently operates without accountability and without legal or ethical oversight, results in epistemic redlining, which she defined as a "hidden ranking system that assigns value and visibility to the humanity, the scholarship, the voices, and the lived experiences of white people or people adjacent to and protective of whiteness" (Scott, 2021b). Epistemic redlining, Scott explained, produces two forms of injustice that undermine Black women's capacity as knowledge generators: (1) epistemic injustice, which "discounts the credibility of Black women's voices and narratives of their own lived experiences" and creates "testimonial injustice," and (2) hermeneutical injustice (Fricker, 2009), which regards Black women as "incapable of making sense of their own experiences and of having them understood by others" (Scott, 2021a).

Scott explained that a deeper analysis of perinatal quality improvement reveals an "abusive" overdependence on quantitative data from "diseased or dead Black female bodies" (Cooper Owens, 2017), resulting in the legitimization of "separate but equal" ethics and practices. "We must interrogate the lie that the absence of clinical pathology signifies the presence of perinatal equity," said Scott. "Thus, we also argue that the perinatal quality improvement epistemology reproduces misogynistic misconceptions about Blackness, Black womanhood, and Black people that undermine our humanity and justice."

The SACRED Birth study, Scott explained, applies Black feminist anthropological theories and methodologies to make an "unapologetic and fierce" declaration of two truths of resistance: (1) "the lives of Black women and people with the capacity for reproduction and pregnancy-related experiences are worthy," and (2) "Black women and people deserve high-quality care experiences that honor the full expression of their humanity, power, and potential."

Scott and her collaborators successfully developed and validated the first and only participatory Patient-Reported Experience Measure of Obstetric Racism©, known as the PREM-OB Scale<sup>TM</sup>. This scale is designed to characterize and quantify the effects of the quality of care on the Black birthing

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patient experience. She emphasized that it was designed through dignified and equitable partnerships with Black women community leaders and scholars. As of the date of this workshop, the SACRED Birth study had validated this instrument through field testing among more than 800 Black mothers and birthing people during the COVID-19 pandemic. Together with Black women–led community-based organizations, SACRED Birth developed a "community-centered, people-focused, hospital-based quality improvement toolkit." The next priority, Scott said, is examining the association between the PREM-OB Scale<sup>TM</sup>, COVID-19 pandemic hospital responses, and birth outcomes and experiences.

SACRED Birth has also started a participatory quality improvement movement. This movement, she explained, is informed by the scholarship of Black women feminist anthropologists who have examined oppression, resistances, and resilience in the Harlem Birthright Project (Mullings et al., 2001), as well as acts of medical racism and obstetric violence characterized by the "explanatory framework" of obstetric racism (Davis, 2019a,b). The study, said Scott, operationalizes Black feminism practices, and reproductive and research justice through cultural rigor<sup>22</sup> (Scott et al., 2020). Traditional survey development processes were adapted by a Black women-led transdisciplinary and transgenerational team of Black women scholars, Black women-led community organizations, a health services researcher, and Black mothers and birthing people. The participatory quality improvement model, she explained, requires completing three easy steps: Name the problem, define the problem through the Black women's intellectual thought and political activism, and design and implement methods to measure, monitor, and modify the problem, and mobilize action based on patient narratives and community wisdom.

Scott described the measure development steps for the study. These seven steps included adopting these explanatory frameworks, co-facilitating focus groups of Black mothers and birthing people in Oakland and Los Angeles led by community and academic researchers, conducting a scoping review of existing patient experience measures using a novel cultural rigor screening protocol, mapping existing items onto domains identified from the focus groups and creating de novo items, administering a modified Delphi survey of primarily Black women subject-matter experts to prioritize items, conducting cognitive interviews with Black mothers and birthing people to refine the items, and writing a final review and compilation for pilot testing by the researchers and

<sup>&</sup>lt;sup>22</sup> Scott et al. (2020) describe the four modalities of cultural rigor as follows: (1) Social movement: Black feminist intellectual thought and political activist in participatory perinatal quality improvement; (2) Analytic framework: reproductive and perinatal apartheid, Sojourner Syndrome, and obstetric racism; (3) Praxis: participatory quality improvement science, practice, and research, PREM-OB Scale<sup>TM</sup>, and Community Driven Virtual Quality Improvement Prioritization Protocol; (4) Vision: #SACREDBirth Movement to #EndObstetricRacism in Hospital Settings.

community accountability partners. Scott added that she applied a Black feminist praxis to the study methodology in order to examine power relations, differentials, and dynamics within the medical industrial complex. The study also utilized a mixed-methods, multicohort participatory approach to center the narratives and lived experiences of 880 Black women and people as patient, content, and community experts.

In closing, Scott asserted that SACRED Birth is igniting a paradigm shift that liberates and redistributes the epicenter of power and knowledge toward Black mothers, birthing people, scholars, and community leaders. In that regard, SACRED Birth represents a first-of-its-kind quality improvement research study. It generates new knowledge to disrupt and transform hospital-based service provision, evaluation, and training through the translation of Black feminist anthropological theory of obstetric racism into novel quality improvement science, practice, and research methods. As part of this effort, SACRED Birth developed the Virtual Quality Improvement Prioritization by Affected Communities or V-QPAC protocol. V-QPAC applies Black feminist ethnographic methodology to identify and describe different forms of resistance and resilience that Black women and community leaders adopt in order to mitigate obstetric racism and power inequities that emerge from supporting Black mothers and birthing people during hospital births.

## Centering Lived Experience and Expertise: Health Equity and Measurement

Presented by Saraswathi Vedam, The University of British Columbia and Birth Place Lab

In the next presentation of the session, Saraswathi Vedam presented on the process and findings of the Giving Voice to Mothers study, which investigates birth experiences using patient-reported outcomes. She opened her presentation with an acknowledgment of the traditional and unceded homelands of the Musqueam, T'sleil Watuth, and Squamish Nations in western Canada, from which she presented.

Over the past decade, global health organizations have focused on describing the types and prevalence of mistreatment during pregnancy and childbirth in low- and middle-income countries, noting that the positive experience of care is an important component of quality and safety, and an outcome in its own right, said Vedam. Unfortunately, she added, measurements of disrespect and abuse in high-resource countries, especially among historically oppressed communities, have not gained the same attention. One reason for that, she said, is that until recently, measures and metrics of person-centered care that have been validated by service users were not available.

In her studies at the Birth Place Lab, she and her collaborators start each study by creating a multistakeholder team led by a Steering Council of service users. Together, they seek funding for a project and co-create the study tools, with the service users instructing them on how to recruit the appropriate study participants and explore the findings. The council also helps identify key messages, create tools for sharing the results, and decide who needs to hear the results and how to tell the stories that best convey the results.

Thanks to this model of co-creation and recruitment, Vedam said that the Giving Voice to Mothers study included participation from all 50 states and robust engagement of communities of color. Their sample had 2,700 individuals (Vedam et al., 2019). Her team coordinated it in collaboration with community health organizations, clinicians, and service users. The Steering Council for this study wanted to understand the care options that are most important to pregnant families in the United States, how communities of color experience care, how families decide where to give birth, whether place of birth or model of care affects their experiences, and in particular, what process of decision making they encounter during pregnancy and birth, including being heard and treated with respect.

The study team developed a survey, available in English and Spanish, through a literature review relevant to the questions that the Steering Council wanted answered. They investigated whether any validated measures were already available to answer those questions. "In fact," said Vedam, "we only found a few measures that the service users felt were relevant to their experience, so we adapted some and we designed some new questions, and then community members went through a formal process of rating each item for relevance, clarity, and importance." The final survey, she added, had quantitative and qualitative items and scales that describe what respectful care and mistreatment looks like from the service user's perspective, measuring experiences of stigma, racism, and abuse as well as supportive, kind, and exceptional care.

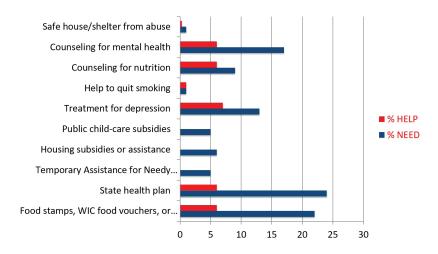
One intent of the study was to elicit data from underrepresented communities. Ultimately, the study team was able to gather data on slightly more than the U.S. population proportion for Black and Indigenous respondents. Vedam noted that participants were able to self-identify with a great amount of detail regarding their race and ethnicity using their own words and own terms. While the survey questions used the terms Native American and Alaska Natives, the results listed those individuals as Indigenous. Half of those in the sample gave birth in hospitals, with the other half giving birth in birth and home centers. While that split is not representative of the choice in birth location in the United States overall, the large numbers in both cohorts enabled Vedam and her team to examine experiences and outcomes by model of care.

One set of questions sought information on mental health and the SDOH. It asked participants if they received various social services during

their pregnancy, and whether their doctor or midwife helped them to meet those needs (see Figure 7). The results show that their providers did not help much. Overall, 21 percent of the participants reported seeking prenatal pregnancy mental health services. Black and Indigenous birthing people were two to three times more likely to have unmet needs for support, said Vedam. Repeating the analysis for people seeking postpartum mental health support produced the same finding. Mistreatment was significantly associated with postpartum mental health visits. Nulliparous participants—birthing people or the people who have the capacity for birthing who had never given birth to a child or who may have lost a child—were 1.4 times as likely to seek postpartum mental health support.

When asked how important is was for them to lead decision making, 91 percent of the participants said it was very important, whereas only 1 percent felt it was not important. About one-third wanted their provider's input. However, in practice, when it came to making a decision about whether to have a cesarean birth, their providers made most of the decisions. Given those

# <u>During your pregnancy, did you feel you needed the following?</u> <u>During your care did your doctor or midwife help you to get?</u>



**FIGURE** 7 Participant responses to the question of whether they received various supports they needed (blue) and if they received help getting them from their physician or midwife (red).

NOTE: WIC = Special Supplemental Nutrition Assistance Program for Women, Infants, and Children.

SOURCE: Workshop presentation by Vedam on June 7, 2021.

results, the Steering Council asked the research team to examine decision making in more depth. Vedam and her collaborators proceeded to analyze the connection between demographics, context of care, and Likert responses on a Mother's Autonomy in Decision Making (MADM) scale with the following choices (Vedam et al., 2017a):

- "My doctor or midwife asked me how involved in decision making I wanted to be.
- My doctor or midwife told me that there are different options for my maternity care.
- My doctor or midwife explained the advantages/disadvantages of the maternity care options.
- My doctor or midwife helped me understand all the information.
- I was given enough time to thoroughly consider the different care options.
- I was able to choose what I considered to be the best care options.
- My doctor or midwife respected my choices."

Summing the responses to each of these items provides what Vedam termed an "autonomy score"; the higher the score, the higher the degree of autonomy. Using these scores as an outcome measure, the researchers found that childbearing people reported significantly lower autonomy when they gave birth in facilities and hospitals, and lower autonomy when they were cared for by hospital-based physicians and midwives versus community-based midwives.

Vedam and her collaborators also examined the responses using the Mothers on Respect Index (MORi) as an outcome measure (Vedam et al., 2017b). This index measures three constructs: (1) how comfortable people felt asking questions and accepting or declining options, (2) whether they felt discriminated against because of their identity or difference of opinion, and (3) how that affected their behavior in terms of whether they would hold back their questions (e.g., because they felt they would be seen as difficult, or had a difference of opinion with the provider). The results of that analysis identified significant differences in experience by race, and found that Indigenous, Black, and Hispanic people reported the lowest levels of respect. When the research team examined the intersection of model of care and place of birth, they found that midwifery clients who gave birth at home or in their freestanding birth center were five times as likely to report very high autonomy and respect compared to patients who gave birth at the hospital or an affiliated birthing center.

Vedam noted that at the direction of the Steering Council, the research team's first analysis and published article focused on the more egregious forms

of mistreatment, such as being shouted at, having treatment withheld, being ignored, or abused physically. They selected these forms of mistreatment at the suggestion of the community members on their Steering Council, many of whom had personally experienced such treatment. One in six birthing people or people with the capacity for birthing in the study experienced one or more types of mistreatment (Vedam et al., 2019). The most frequently reported form of mistreatment was "being shouted at or scolded by a health care provider." The next most common types were "health care providers ignoring the participants, refusing their request for help, or failing to respond to requests for help in a reasonable amount of time." A large proportion of the participants—including one-third of those who are Black, Indigenous, or a person of color (see Figure 8)—described being threatened with the possibility of their baby's death (Vedam et al., 2019). Vedam noted that WHO has found that birthing people or people with the capacity for birthing in marginalized communities globally, among low- and middle-income countries, experience similar rates of mistreatment (see Figure 8).

She also said that the rate of mistreatment increased significantly when the participants had an unplanned intervention (such as an instrumental vaginal birth or unplanned cesarean section), or when they gave birth in a

## Mistreatment by population





I in 3 in LMICs, and BIPOC communities Lancet 2019, Reproductive Health 2019

1 in 6 (17%) experienced mistreatment in full sample

### **FIGURE 8** Mistreatment by population.

NOTES: Two studies, one with an international sample of birthing people and one with a sample of birthing people in the United States (Vedam et al., 2019), found similar rates of mistreatment among their respective samples. BIPOC = Black, Indigenous, people of color.

SOURCES: Workshop presentation by Vedam on June 7, 2021; Vedam et al., 2019.

hospital, a birthing center inside a hospital, or if they were transferred from a community birthing center or at home. Not surprisingly, said Vedam, birthing people or people with the capacity for birthing who were immigrants or of low socioeconomic status, who had a risky pregnancy, or who were at risk socially experienced higher levels of mistreatment. Stratifying the data by race showed that childbearing people of color were suffering the highest levels of mistreatment.

In terms of consent and non-consent to procedures and pressure to accept interventions, the analysis showed that while about half of the respondents said they declined some aspect of care, childbearing people of color were more likely to have care providers perform the procedure against their will or to continue asking them until they agreed. Being Black, Indigenous, or a person of color accounted for 39 percent of the variability in non-consent procedures, and significantly predicted pressure to accept a procedure, said Vedam.

Vedam noted that measuring the quality of maternity care through patient-reported outcomes is critical to understanding health inequities among communities and regions that carry the disproportionate burden of adverse outcomes. Among respondents from the southeast United States, the odds of any mistreatment, low autonomy, or low respect were higher among Black birthing people and birthing people from other communities of color. Irrespective of participant race, midwifery care in community birth settings was protective against mistreatment, low autonomy, and low respect, compared to giving birth in the hospital. "But access to midwifery, as we know, is very inconsistent, and often not paid for state by state," said Vedam. Another group who experienced higher levels of mistreatment were larger people, who were almost five times as likely as those with a "normal" body mass index to report that they experienced a loss of autonomy, received no response when they requested help, or were shouted at, scolded, threatened, or ignored.

These findings matter, said Vedam, because research has shown that being ignored or experiencing delays in response to requests for help are directly related to maternal deaths (Mitchell et al., 2014). "Leave aside that these are outcomes in their own right and human rights issues, it is difficult to ignore that mistreatment, and the way people are treated and experience care is a quality-of-care issue," she said.

In addition to measuring the factors that cause harm, the research team asked the participants about who helped them to survive, succeed, and thrive when they experienced problems. The answers showed that it was not the health care system, health care providers, or the government that helped, but rather family, friends, the faith community, and other community-based supports. In fact, though respondents noted that finding a doctor or midwife who shared their heritage, race, ethnic, or cultural background was important, it was also quite difficult, particularly if they were Black, Indigenous, or Latinx.

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In a study of the impact of culturally centered care in community birth centers, researchers found that the clients of the Roots Community Birth Center in Minneapolis, a Black-led community birth center, had significantly higher scores on measures of autonomy and respect compared to the clients who were not in community birth settings. These findings held when comparing scores for those who are Black, Indigenous, and people of color (Hardeman et al., 2019).

In closing, Vedam noted that these tools have been used globally in more than 40 countries since 2017, but they are just now getting some uptake in the United States. She added that there is a cadre of early career scholars of color still poring over the huge data set her team has produced. As a final remark, she asked the participants to ponder what the effect would be if the research community changed the way it looked at studying birth. "What if we measured undisturbed birth rates alongside cesarean rates and upright spontaneous birth alongside vacuum and forceps assisted? What if we looked at the effects of model of care, respect, and disrespect alongside service delivery, and the impact of place of birth, and of course the impact of racism and antiracism in health care?"

### Maternal Mortality and Medical Misogynoir<sup>23</sup>

Presented by Brownsyne Tucker Edmonds, Indiana University School of Medicine

To open her presentation, Brownsyne Tucker Edmonds reiterated that the United States is one of the most dangerous industrialized nations to give birth in. For Black birthing people, who experience three to four times the rate of maternal mortality compared to white birthing people, the risk of dying in or after pregnancy rivals that of low-income or developing nations. She noted that the latest science on weathering has helped develop a framework for how structural and systemic inequity, experienced and embodied as chronic stress, accumulate over an individual's life course, and can even have an impact across multiple generations. They create physiological disruptions that increase the allostatic load and accelerate cellular aging and disease risk in Black women, resulting in inequitable health outcomes for Black women (Geronimus et al., 2020; see Figure 9).

When she was preparing this presentation, Tucker Edmonds said, her mind went to Serena Williams, who suffered a postpartum embolism following the birth of her daughter. She was dismissed as confused even as she

<sup>23</sup> This presentation focuses on the experience of Black women in particular, but many of these dynamics are also harmful to Black birthing people of other gender identities.



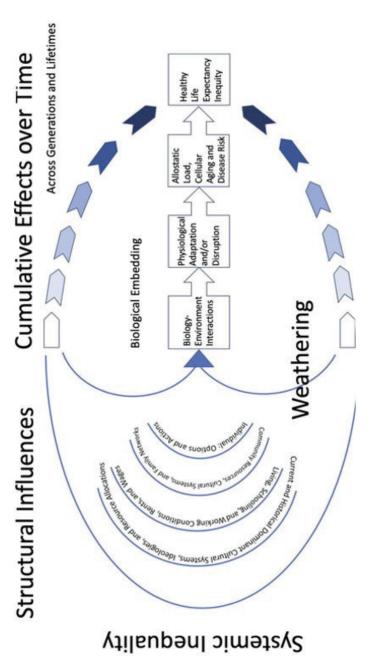


FIGURE 9 A structural framework for understanding how structural and systemic inequity produces inequitable health outcomes for Black birthing people. SOURCES: Workshop presentation by Tucker Edmonds on June 7, 2021; from Geronimus et al., 2020.

told the health care providers exactly what her diagnosis was, and exactly the diagnostic testing and treatment that she needed. The public at the time was dumbfounded and genuinely perplexed when they read about this as to how the most famous tennis player in the world could be dismissed, diminished, and disbelieved in that moment.

To understand why even fame and fortune cannot protect a Black woman as well known and informed as Serena Williams requires understanding how bias operates distinctly against Black women, a phenomenon known as misogynoir. This term, coined by Black feminist scholar Moya Bailey, describes a specifically anti-Black racist form of misogyny that Black women experience through stereotypes, violence, oppression, and dehumanization. Tucker Edmonds noted that Serena Williams (as well as Michelle Obama and Meghan Markle) has been victim to misogynoir since she stepped into the public eye. This has taken the form of unbecoming depictions of Black women, such as the angry Black woman; the hypermasculine, manly renderings that appeared in the press; or conversely, the hypersexual "catsuit" depictions.

This particular form of violence and dehumanization against Black women has its roots, like most forms of anti-Black racism, in the nation's history of chattel slavery. In 1662, Virginia adopted the legal doctrine of *Partus Sequitar Ventrum*, which stipulated that the enslavement status of the child would follow that of the mother, making enslavement an inheritable status. Once Black children were legally born into slavery, Black childbearing became central to the enterprise of slavery, and society came to monetize, commodify, and exploit Black women's labor on three fronts: their physical labor, their reproductive labor, and their emotional labor, explained Tucker Edmonds.

She noted that white racist ideology has always tried to position itself as being aligned with the deeply held virtues of white reason, enlightenment, and morality. As such, racist narratives emerged to justify the treatment of Black women—they became archetypes and ideologies that essentialize Black women as existing for the sole purposes of the functions they served for the white man:

- The Mammy, for example, is submissive and exists for emotional labor, putting aside her own needs in service of the white's caretaking and domestic servitude. In more contemporary portrayals, she serves as the "Black best friend," there to offer moral support, but two-dimensional in her own right.
- The Jezebel exists for reproductive labor; someone who meets the sexual
  and economic interests of white men, she is a seductress, hypersexual,
  and born to breed. Her contemporary rendering would give rise to
  Welfare Queen tropes.
- The Sapphire is sassy or aggressive and exists for physical labor because she is hypermasculine, emasculating, and aggressive. She would become the outspoken "Strong Black woman" or the belligerent "Angry Black

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woman" whose aggression emasculates Black men and threatens white people.

"Once you start to look for these patterns in our media, in public spaces and public discourse, you start to see these patterns of hypermasculinization and hypersexualization everywhere you look, from manly Michelle to emasculating or seductive Meghan," said Tucker Edmonds. She added that obstetric racism is, in fact, rooted in these two-dimensional depictions and reductive ideologies that deny Black women the full range and experience of human emotion, suffering, and pain. "That J. Marion Sims experimented on enslaved Black bodies to become the 'Father of Modern Gynecology' reminds us that our profession's origin story arises from the dehumanization of Black women," she said.

Tucker Edmonds said she sees obstetric racism as a form of medical misogynoir, a system of care that is both neglectful and judgmental and that plays out in the deprioritization of people of color. It plays out, too, in the judgments about Black pregnant people's fitness to parent. This results in a greater number of social work consultations, and referrals by providers to child protective services and the criminal legal system. Medical misogynoir also manifests in the challenging of the validity of Black birthing people's pain complaints, which result in inadequate pain management during and after delivery. Providers often challenge a patient's respectability on the grounds of a range of issues, including age, marital status, and appearance. These attitudes too frequently result in demeaning behaviors and insensitive comments about baby daddies or Black-sounding names (Sigurdson et al., 2018). Women of color also express that power dynamics, interpersonal racism, and judgmental attitudes influenced how health care providers chose to share information with them, which had a meaningful impact on their ability to control decision making (Altman et al., 2020).

With these dynamics in mind, Tucker Edmonds studies shared decision making as a model of care. She thinks of decision making in terms of shared power, and views it as a model of care that may mitigate maternal health inequities by humanizing, elevating, and centering Black pregnant people. She presents an acronym organizing the terms of Shared POWER as shared "Priorities, Outcomes, Wants, Expertise, and Responsibility." In the shared decision-making model, the clinical encounter is structured around shared priorities in which clinicians create a shared agenda by inviting patients to tell them their "must discuss" items to ensure their concerns are addressed. Clinicians then manage expectations about the desired and most probable outcomes depending on their patient's expressed goals of care. "We attend to patient's wants, eliciting their preferences and values to align them with treatment plans," said Tucker Edmonds. "We acknowledge a patient's expertise in their lived experience and engage in bidirectional exchange of information

and expertise, and we take on shared responsibility in partnering to make a decision together."

Shared decision making, however, only attends to the interpersonal aspects of implicit bias and obstetric racism. These efforts, she said, have to be paired with systemic and structural changes for meaningful change to occur. The development of patient-centered models of care will need to integrate frameworks for trauma-informed care and reproductive justice into the manner in which the health care system delivers reproductive health care across the life course. Within the realm of obstetrics, this will require integrating medical and midwifery models of care to ensure that Black birthing people are afforded the full spectrum of supports they need.

Tucker Edmonds noted that in 2019, she served on the consensus study committee that produced the National Academies report, *Birth Settings in America: Outcomes, Quality, Access, and Choice* (NASEM, 2020). That committee, she said, spent a great deal of time wrestling with how to attend to a dual reality: Patient-centered midwifery models may mitigate harms and disrespect experienced by and directed toward Black birthing people; at the same time, the effects of systemic racism and weathering have physiologic consequences that render Black birthing people more vulnerable to medical and obstetrical morbidity that may be most safely managed by medical teams in hospital settings. "While current debates are focused on whether Black women would fare better birthing in hospitals or out of hospitals, my hope is that we will move away from these either/or strategies, to forge more integrative models of care," said Tucker Edmonds. "I fully believe that Black women are deserving of both/and."

She concluded her comments with a quote by the Combahee River Collective, a Black feminist movement named after the Union Army raid that Harriet Tubman led in 1863 to liberate 750 enslaved people in South Carolina. "If Black women were free, it would mean that everyone else would have to be free, since our freedom would necessitate the destruction of all the systems of oppression."

# Birthing Experiences in Care Settings: Pregnant People Experiencing Incarceration

Presented by Carolyn Sufrin, Johns Hopkins University

"If we are to understand the structural and historical forces that shape racialized differences in maternal morbidity and mortality in this country, and if we are to understand how our society has differentially devalued some people's reproduction while promoting others, then we must look to what is happening behind bars in the United States," said Carolyn Sufrin to start her presentation. She noted that what happens in prisons, jails, and detention

centers, which are largely shielded from oversight, not only reveals much about the individuals who are trapped behind these bars, but it also about how society treats marginalized people and their reproductive well-being when no one is paying attention.

People who are pregnant or give birth while incarcerated do so at the intersection of health care, carceral, and child welfare or family regulation systems<sup>24</sup> that have historically oppressed and traumatized birthing people of color. In the United States, said Sufrin, there has been an exponential rise over the past four decades in the number of incarcerated people. This phenomenon of mass incarceration has its origins in overlapping policies and legacies, including Jim Crow segregation, slavery, and all the systems of oppression that undergird American society. What is often left out of conversations about mass incarceration is the fact that women have been the fastest growing segment of the incarcerated population, with a 750 percent increase over the past four decades (The Sentencing Project, 2020; see Figure 10). The majority of these women are between 18 and 45 years old (Carson, 2020), 60 percent are mothers to young children (Maruschak et al., 2021), and 70 percent were arrested and sentenced for minor charges (FBI, 2020), which has a profound ripple

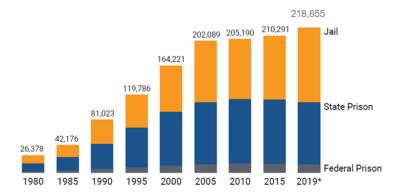


FIGURE 10 The rise in the number of incarcerated women, 1980–2019.

SOURCES: Workshop presentation by Sufrin on June 7, 2021; adapted from The Sentencing Project, 2020; Bureau of Justice Statistics: Historical Corrections Statistics in the United States 1850–1984 (1986); Prison and Jail Inmates at Midyear Series (1997–2018), Prisoners Series (1986–2019). Washington, DC.

<sup>\*</sup> Prison figures are from year-end 2019 while jail figure is from year-end 2018, the latest available data from the sources used.

<sup>&</sup>lt;sup>24</sup> This phrase is used in place of the "child welfare system." This system not only impacts children but also the entire ecosystem around them. The misnamed "child welfare" system, like the misnamed "criminal justice" system, is designed to regulate and punish black and other marginalized people (Williams, 2020).

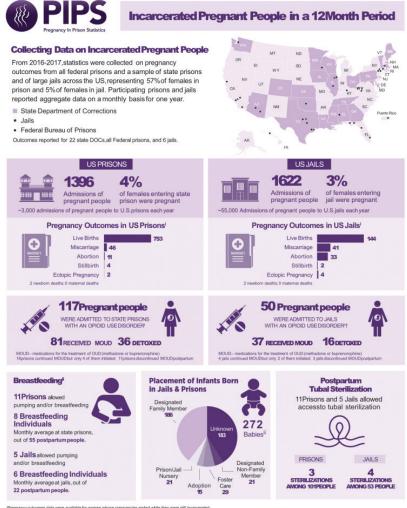
effect on the children, families, and communities they leave behind. Sufrin noted that everything about mass incarceration disrupts the core principles of reproductive justice.

While it is known that Black women are incarcerated at twice the rate of white women (Zeng, 2019), this statistical fact belies a complex intersection of forces. "When we talk about racial disparities and racial inequities in incarceration rates, it plays out in a very distinct way for women compared to men who are incarcerated in this country," Sufrin explained. "That is because of the unique and distinct and deeply problematic overlap between policies that criminalize certain behaviors in pregnancy, such as substance use disorders, rather than providing people with access to medical treatment." She noted that mass incarceration in the United States has become a strategy of social and racial control that is intertwined inextricably with the nation's family regulation system (Goodwin, 2020).

Sufrin and her team estimated how many pregnant people are behind bars. To do so, they drew on 1 year of monthly pregnancy data from 22 state prison systems, all federal prisons, and the five largest county jails in the country. In the year ending in December 2016, there were 1,396 admissions of pregnant people to the sampled U.S. prisons, with 4 percent of newly admitted women and 0.6 percent of all women entering prisons being pregnant, producing a total estimate of around 3,000 admissions of pregnant people to prisons in the United States each year. There were 753 live births, 46 miscarriages, 11 abortions, 4 stillbirths, 3 newborn deaths, and no maternal deaths. Six percent of these live births were preterm and 30 percent were cesarean deliveries (Sufrin et al., 2019). Sufrin also presented their findings for pregnant people in U.S. jails, as opposed to prisons. In addition, there were 1,622 admissions of pregnant people to the sampled U.S. jails, with about 3 percent of females entering being pregnant, producing an estimate of around 55,000 admissions of pregnant people to jails in the United States each year. Of the 224 pregnancies that ended in the jails surveyed, 144 were live births, 41 were miscarriages, 33 were abortions, 4 were ectopic, 2 were stillbirths, 1 was a newborn death, and there were no maternal deaths. One-third of the births were cesarean deliveries and 8 percent were preterm (Sufrin et al., 2020; see Figure 11).

Sufrin noted a few key gaps in the data that her team was able to collect. They could not disaggregate these data by race or ethnicity, because the jails and prisons do not report on that level, nor was she able to collect data about morbidity. While there were no deaths reported in her study sample, that does not mean it does not happen. She echoed Abigail Echo-Hawk's suggestion that multiyear aggregation of data should be done.

She then turned her attention to the care that birthing people receive while incarcerated. She explained that there is a constitutional requirement



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**FIGURE 11** Incarcerated pregnant people in a 12-month period, 2016–2017. SOURCES: Workshop presentation by Sufrin on June 7, 2021; originally posted to https://arrwip.org (accessed August 18, 2021).

that institutions of incarceration must provide health care to incarcerated people; not to do so is considered cruel and unusual punishment and therefore presents a violation of the Eighth Amendment (Sufrin et al., 2020). While the Supreme Court affirmed this requirement in 1976, it was not the Court's job to delineate the quality of those services or what they must include. With no mandatory standardization of care and no system of accountability or oversight, the care provided in prisons and jails is highly variable and inconsistent, said Sufrin. In fact, 12 states have no prenatal care policy for incarcerated birthing people (Daniel, 2019), 24 have no preexisting arrangements for delivery (Daniel, 2019), and one-third of the pregnant people who had an opioid use disorder (OUD) were forced to go through withdrawal, contrary to medical guidelines. The majority of the birthing people who did receive medication for opioid use disorder (MOUD)<sup>25</sup> therapy were given methadone instead of buprenorphine; again, contrary to medical guidelines. In addition, many lack access to nutritional and environmental conditions conducive to nurturing a gestating pregnancy.

Sufrin pointed out that there are some prisons and jails that do provide standard pregnancy care at a reasonable level of quality, but many do not. While behind bars, she said, birthing people have variable access to medical and mental health care. They may be provided care from a qualified perinatal care provider, such as a certified nurse midwife, a nurse practitioner with obstetrical training, or an obstetrics/gynecology or family medicine physician. In many cases, they may not, and care may come instead from a provider who has never received any training in the care of pregnant people. "If you are a person who is incarcerated and you have contractions, or you are having vaginal bleeding or a severe headache that could be a sign of preeclampsia, you rely on guards as gatekeepers for access to care, so they by default become your triage person," said Sufrin.

She noted that it is isolating to be pregnant and incarcerated without the usual social supports, and people have a lot of uncertainty about what their rights are. While they have more than most of them think, they also have many of their rights and their sense of bodily autonomy intentionally taken away from them. They often have a lot of uncertainty and worry about what is going to happen to them during their birth experience, or to their children. Being incarcerated also means they cannot decide when they eat or what

<sup>&</sup>lt;sup>25</sup> MOUD refers to the treatments for OUD that include opioid agonist or antagonist medications (NASEM, 2019). The term medication assisted treatment (MAT) is also commonly used; however, the National Academies prefer the use of MOUD because it better aligns with the "conceptual framework of OUD as a chronic disorder for which medications are first-line treatments that are often an integral part of a person's long-term treatment plan, rather than complementary or temporary aids on the path to recovery" (NASEM, 2019, p. 18).

they eat. They have to ask permission to use the bathroom, and they sleep on uncomfortable mattresses.

Even when they are taken to the hospital, hospitals are also barriers for quality and respectful care for incarcerated people, explained Sufrin. "In addition, since incarcerated people are disproportionately Black and other people of color, they already experience all of the baseline disrespectful care and challenges that we have heard about today," she added. On top of that, research has shown that incarcerated patients experience a synergistic level of stigma and discrimination, and one study of nearly 700 perinatal care providers found that stigmatizing attitudes toward incarcerated people were associated with lower intentions to provide standard-of-care pregnancy care (Goshin et al., 2020). Incarcerated birthing people who give birth in a hospital cannot have visitors in most cases, and they may be shackled during labor, said Sufrin. Although 34 states have laws prohibiting this practice, the laws are not always implemented because incarcerated birthing people are so devalued (Goshin et al., 2019). There may be a uniformed officer in the room during birth—an extreme invasion of privacy. After birth, some hospitals have a practice of immediately separating the new parent from their newborn (Franco et al., 2020). Some prisons or jails will expedite postpartum discharge so they do not have to keep paying for a guard's overtime to be stationed at the hospital.

There are successful models of doula support for incarcerated pregnant and birthing people that provide support throughout the pregnancy and birth and postpartum process (Schroeder and Bell, 2005). Sufrin noted that these models are feasible to implement, have high satisfaction and acceptability rates, and can provide necessary support and a patient advocate.

When the birthing person returns to prison or jail, the question of who cares for the infant becomes paramount. In some cases, there might be a family member available to provide care, but in many cases there may not be someone who a birthing person can rely on. In such cases, the infant goes into the foster care system. For a birthing person with an OUD who was given methadone or buprenorphine during pregnancy, Sufrin's research has shown that the majority of prisons and jails will discontinue it postpartum. What that says to her is that the concern of the prison or jail is for the pregnant person only inasmuch as they are carrying a fetus, but as soon as that pregnancy is over, they stop the evidence-based treatment for her health and well-being.

She also noted that there are tremendous issues and concerns regarding mental health and trauma, especially of being forcibly separated from one's newborn when the birthing person goes back to prison. Yet, mental health care in prisons and jails is sorely lacking, and there are little to no data about the prevalence of postpartum depression and other postpartum mental illness.

Although breastfeeding while incarcerated is feasible, and some prisons and jails do make that possible, it is extremely challenging even when all the

systems are in place. "In most cases, it is going to be expression of breast milk and figuring out systems to transport that milk from the prison or jail to the infant's caregiver," said Sufrin.

In closing, Sufrin said that the primary need is to end all carceral births. She calls for all states to follow the lead of states such as Minnesota, which recently passed the Healthy Start Act to end incarceration of pregnant people and allow them to be with their babies for 1 year after birth. Until carceral births and mass incarceration end, though, there are actionable steps for harm reduction that can improve the quantity and quality of care. These include setting mandatory standards of care and oversight; providing access to doulas; training custody and carceral medical staff; reducing harm from hospitals by providing trauma-informed care and security protocols and prolonging infant contact and postpartum recovery; providing breastfeeding support; providing postpartum and pregnancy mental health care; and passing and implementing anti-shackling laws.

## MATERNAL HEALTH AND COVID-19: EXACERBATING VULNERABILITIES AND USE OF TECHNOLOGY

The workshop's fourth session discussed the experiences of birthing people during the unprecedented period of COVID-19, and the experience with technology to provide and receive services. The three speakers in this session were Stephanie Gaw (University of California, San Francisco), Allison Bryant (Massachusetts General Hospital), and Nia Mitchell (NBEC).

# Maternal Morbidity with COVID-19 in Pregnancy and the PRIORITY Study

Presented by Stephanie Gaw, University of California, San Francisco

At the start of the COVID-19 pandemic, said Stephanie Gaw, little was known about the effects that the SARS-CoV-2 virus would have on pregnant people. An early WHO analysis of 147 pregnant people who developed COVID-19 concluded that the risks to pregnant people appeared to be no greater than for anyone else. At the time, only 8 percent of that small cohort had severe disease, and only 1 percent were in critical condition. As a result, the initial clinical practice advisory from ACOG issued on March 13, 2020, stated "Currently available data on COVID-19 does not indicate that pregnant women are at increased risk. However, pregnant women are known to be at greater risk of severe morbidity and mortality from other respiratory infections such as influenza and SARS-CoV-2. As such, pregnant women should be considered an at-risk population for COVID-19" (ACOG, 2021).

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That practice advisory was revised several times over the next few months, and when ACOG issued an advisory on December 14, 2020, it stated, "Available data suggest that pregnant women with COVID-19 may be at increased risk for more severe illness compared with nonpregnant peers. Given the growing evidence, CDC now includes pregnant women in its "increased risk" category for COVID-19 illness.... Importantly, analyses so far are limited by a large amount of missing data" (ACOG, 2020).

Over the past year, said Gaw, so much data have come out on COVID-19 in general, and specifically regarding COVID-19 in pregnancy, that it is hard to sift through all of it. WHO does have an ongoing project, Pregnancy in COVID-19 Living Systematic Review and Meta Analysis (Allotey et al., 2020), that is trying to analyze the data in real time in order to provide a clearer picture of the true outcomes of maternal and perinatal COVID-19 disease, on a global level. As of February 2, 2021, the project had synthesized the findings from 192 studies on nearly 65,000 pregnant or recently pregnant people (see Table 1), and the plan is to issue continual updates for up to 2 years.

Overall, when the project's investigators compared outcomes for pregnant people with COVID-19 versus for nonpregnant people with COVID-19, they did find an increase in severe disease, including a 2-fold increase in intensive care unit (ICU) admissions, a 2.6-fold increase in invasive ventilation, and a 2-fold increase in extracorporeal membrane oxygenation and other measures of severe illness. There was also a 17 percent increase in preterm birth for pregnant people (6 percent of which were spontaneous), versus for birthing people without COVID-19. They also found an increase in stillbirth, neonatal death, and NICU admissions, but no significant increase in cesarean deliveries, globally (see Table 2).

**TABLE 1** Maternal Outcomes for Pregnant Women Who Develop COVID-19

Maternal Outcomes	Versus Nonpregnant with COVID-19 OR (95% CI)
Mortality	0.96 (0.79–1.18)
ICU admission	2.13 (1.54–2.95)
Invasive ventilation	2.59 (2.28–2.94)
ECMO	2.02 (1.22–3.34)
O2 supplementation	0.21 (0.04–1.13)
ARDS	1.51 (0.03–79.93)
Major organ failure	1.51 (0.03–79.93)

NOTE: ARDS = acute respiratory distress syndrome; CI = confidence interval; ECMO = extracorporeal membrane oxygenation; ICU = intensive care unit; O2 = oxygen; OR odds ratio.

SOURCES: Workshop presentation by Gaw on June 7, 2021; Allotey et al., 2020.

When the researchers examined the international data for factors associated with increased risk of severe outcomes, increased age, increased body mass index, non-white ethnicity, and medical comorbidities were frequently associated with measures of increased COVID-19 severity, including admission to the ICU, invasive ventilation, and maternal death (see Table 3).

Addressing the strengths and limitations of this work, Gaw characterized it as a rigorous meta-analysis of all available international studies that WHO will continue to update. Its limitations include the heterogeneity of the studies and the data, that the outcomes are primarily from hospital-based diagnoses, that the study is still waiting for data on first trimester infections, and that it needs to include more studies with contemporaneous pregnant comparison groups rather than relying on historical controls.

To address some of these limitations, Gaw and her colleagues launched the Pregnancy Coronavirus Outcomes Registry (PRIORITY) Study in March 2020 to assemble a nationwide cohort of COVID-19 infections in pregnancy that includes all pregnant people 13 years and older who are pregnant (or were pregnant within 6 weeks) and who are under investigation or with a confirmed diagnosis of COVID-19 by a reverse transcription polymerase chain reaction (RT-PCR) test since January 2020. Gaw explained that participants can enroll in any language from any site across the country, whether it be private practice, academic hospitals, or midwifery practices, and if they are medically unable to self-consent (e.g., if they are ventilated), then a family member can provide proxy consent.

Gaw said that patients can self-enroll, enroll through provider referrals, or enroll through community partner referrals at the University of California, San

**TABLE 2** Perinatal Outcomes for Pregnant Women Who Develop COVID-19

Perinatal Outcomes	Versus Pregnant Without COVID-19 OR (95% CI)
Preterm birth <37w - 17% (6% spontaneous)	1.47 (1.13–1.91)
Cesarean delivery	1.12 (0.91–1.38)
Stillbirth	2.84 (1.25–6.45)
Neonatal death	2.77 (0.92–8.37)
NICU admission	4.89 (1.87–12.81)
Low 5m APGAR	1.38 (0.71–2.70)
Fetal distress	2.37 (0.77–7.31)

NOTE: CI = confidence interval; NICU = newborn intensive care unit; OR = odds ratio.

SOURCES: Workshop presentation by Gaw on June 8, 2021; Allotey et al., 2020.

Any comorbidity 1.8 (1.5–2.2)

2.0(1.1-3.5)

1.4 (0.9-2.4)

2.1 (1.6-2.8)

1.2(0.7-2.1)

4.2 (1.3-14.0)

Chronic

diabetes Gestational

diabetes Preeclampsia

hypertension Asthma

Pregestational

	OR (95% CI)			
Risk Factors for Severe Outcomes	Severe Disease	ICU Admission	Invasive Ventilation	Maternal Death
Age ≥ 35 y	1.8 (1.3–2.6)	2.1 (1.7–2.6)	1.7 (0.6–5.0)	0.9 (0.2–3.7)
BMI ≥ 30	2.4 (1.8–3.1)	2.7 (1.1–6.6)	6.6 (2.0–22.0)	2.3 (1.2-4.3)
Non-white ethnicity	0.9 (0.6–1.6)	1.7 (1.2–2.3)	2.2 (1.3–4.0)	1.6 (1.05–2.5)

1.7 (1.3–2.2)

4.7 (2.4-9.4)

2.9 (0.5–16.7)

4.7 (1.9–11.2)

3.3 (1.6–6.9)

179.4 (7.7– 4,168) 5.3 (1.8-15.7)

63.8 (9.7–420.5) 4.3 (1.8–10.0)

18.6 (0.3–1,324) 14.9 (4.2–52.8)

2.5(0.8-8.2)

1.7 (0.7-4.2)

**TABLE 3** Risk Factors for Severe COVID-19 Illness

NOTE: BMI = body mass index; CI = confidence interval; ICU = intensive care unit; OR = odds ratio.

SOURCES: Workshop presentation by Gaw on June 8, 2021; Allotey et al., 2020.

Francisco, Central Coordinating Center.<sup>26</sup> Participants in the study complete weekly questionnaires for 4 weeks after enrolling, at each trimester, at term, and at specific intervals after the end of pregnancy. Medical records are also reviewed for every participant, in order to gather details on hospitalization, delivery, and neonatal outcomes. Mother–baby dyads are followed through 12 months of age. The PRIORITY Study managed to enroll people from every state except North Dakota and Arkansas.

There will be four outcome scores for the study: (1) maternal outcomes, (2) infant outcomes, (3) reproductive health equity and birth justice, and (4) biospecimen collection results. The goals for each of the four outcomes, respectively, are to (1) provide comprehensive data on the medical and clinical outcomes from COVID-19 in pregnancy; (2) do the same for the infant outcomes out to 1 year of age; (3) investigate both the clinical outcomes and the patient experience of pregnant Black, Indigenous, and people of color during the epidemic regarding the care they receive for COVID-19; and (4) try to understand some of the biologic roots of disease and disparities. A parallel

<sup>&</sup>lt;sup>26</sup> See https://priority.ucsf.edu (accessed August 14, 2021).

study, PRIORITY-B, is collecting biospecimens at six hospitals across the nation for further study of disease transmission and the immune response in the mother–baby dyad.

The reproductive health equity and birth justice core, led by Monica McLemore, has worked to engage Black, Indigenous, and people of color communities in an authentic, transparent, and meaningful way. Gaw explained that this is being done by supporting increased enrollment of participants in these groups and by using targeted survey instruments to understand their individual experiences with racism and access to care during COVID-19. This core has a national community advisory council, and has also engaged Research Priorities of Affected Communities<sup>27</sup> to help prioritize questions that community members most affected by the COVID-19 pandemic may have.

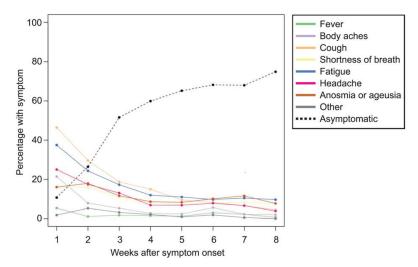
In total, of the 1,333 participants enrolled in PRIORITY, 853 were COVID-19 positive, 239 were negative, and there were 241 "others." At the time of the workshop, 185 were pregnant and 1,148 were recently pregnant. Gaw and her colleagues were still waiting on the collection of data about additional pregnancies, which will be due at the end of April 2021, in order to perform their final analyses. In the first paper to come from the study, Gaw and her colleagues found that COVID-19 had a prolonged course of symptomatology in about 25 percent of pregnant people reporting symptoms after 8 weeks (see Figure 12), and that approximately 95 percent of the participants were not hospitalized (Afshar et al., 2020). The most common symptoms after 8 weeks were fatigue, shortness of breath, loss of taste and smell, and cough.

A second paper, covering the first 263 births, showed that there were no significant adverse outcomes in these pregnancies and that most of the babies born to COVID-19-positive mothers were healthy (Flaherman et al., 2020). No babies had respiratory infections, pneumonia, or a need to be hospitalized in the first 6 weeks after birth, and only two infants tested positive at 24 hours after birth.

In closing, Gaw listed some of the forthcoming data that the project will release on maternal and neonatal outcomes, including neurodevelopment sequelae in the infants. One member of the research team is heading a side project, PRIORITY-VOICE, in which she interviewed 40 birthing people to explore their perceptions of and experiences with engaging in maternity care. That project will also "identify barriers to engaging in maternity care and possible solutions on how to improve prenatal and birthing care experiences." 28

<sup>&</sup>lt;sup>27</sup> A novel method for involving women of color at high risk for preterm birth in research priority setting (Franck et al., 2018).

<sup>&</sup>lt;sup>28</sup> See https://birthjustice.ucsf.edu/priority-voice-study (accessed August 17, 2021) for more information.



**FIGURE 12** COVID-19 has a prolonged course of symptoms in 25 percent of pregnant patients.

SOURCES: Workshop presentation by Gaw on June 7, 2021; Afshar et al., 2020.

In addition, the PRIORITY-B project has enrolled more than 300 participants and collected more than 200 dyad samples.

# Maternal Health Inequities: Lessons Learned (and Re-Learned) from the COVID-19 Pandemic

Presented by Allison Bryant, Massachusetts General Hospital

Quoting a speech by Dr. Mary Bassett, Allison Bryant reflected that "epidemics and pandemics uncover the fissures in our society."<sup>29</sup> It came as no surprise, said Bryant, to see the inequities in COVID-19 infection rates, hospitalizations, and death rates. She likened what is happening with COVID-19 to a mathematical model in which there is an interaction between the severity and quality of different exposures—in this case, a hazardous event—and the sensitivity of those affected; this then has effects on both short- and long-term outcomes. She also noted that she often points out that the health inequities the United States is experiencing did not occur by accident, but

<sup>&</sup>lt;sup>29</sup> See https://abcnews.go.com/Health/covid-19-exposing-cracks-us-health-system-experts/story?id=70408044 (accessed August 14, 2021).

were designed by the legacy of chattel slavery, Jim Crow segregation, and the lingering structural racism that the nation's systems leverage to elevate some groups over others.

When considering the contributors to health and health care inequities, Bryant described a similar framework to those laid out by the other presenters at the workshop. She noted that models suggest that inequities arise from provider-, patient-, and health care system—level factors. However, she said, structural factors such as poverty, unemployment, housing instability, food insecurity, and both structural and interpersonal racisms dwarf other components in terms of their contributions to health and health care inequities.

During the COVID-19 pandemic, there has been a great deal of discussion about the role of the SDOH in producing the disparities seen in infection, hospitalization, and death rates. "I do think that these are important because the integrity of each of these is so interwoven with the community's ability to respond to a crisis," said Bryant, "but I think as Dr. Crear-Perry said earlier, we really cannot talk about social determinants of health without understanding the underlying contributors to social determinants of health, which really are structural racism." Underlying policies such as redlining, segregation, and the different effects of the GI Bill after World War II<sup>30</sup> led to differential SDOH. Of special note, she pointed out, these were in turn ultimately associated with differential rates of hypertension and diabetes, which have had direct correlates with COVID-19 incidence and outcome.

The problems that led to the disparities seen with COVID-19 had many origins, said Bryant. For example, she noted, the living and working circumstances of many of her patients made social distancing and in-home isolation challenging. In addition, many public health messages were not delivered in multiple languages, an important contributor to the inequities in the multilingual community in Boston in which she works. The prevention mechanism home confinement—led to increases in the risk for gender-based violence and mistreatment that were particularly concerning for those households with fewer resources. In addition, racist and xenophobic attitudes were a threat to patients as well as the health care workforce. Access to testing was not uniform by population. Adding to the disparities, the comorbid conditions that are risk factors for severe COVID-19 illness are differentially distributed in the United States as a result of long-standing inequities in access and quality care, a result of structural racism. In obstetrics, as other speakers have noted, these concerns overlay the backdrop of the maternal morbidity and mortality crisis in the United States, particularly for Black birthing people.

<sup>&</sup>lt;sup>30</sup> See https://www.history.com/news/gi-bill-black-wwii-veterans-benefits (accessed August 19, 2021).

To approach the COVID-19 pandemic in terms of health equity, her institution kept a running list of topics that staff felt they could get a handle on within their health care system. One item, for example, was looking at how bias and mistreatment were showing up in everyday care of patients. They also examined what their data systems were collecting and reporting and how they could make best use of that to serve the communities in greatest need. Thinking about community health and issues of reproductive justice were particularly important to her department of obstetrics and gynecology.

As the institution moved forward and started thinking about reopening and recovery, Bryant said an emphasis was placed on continuing its effort to limit the spread of COVID-19 in its particular hotspots, and to focus on social needs. She and her colleagues started thinking about being intentional about the equitable reopening of the health care system and applying the lessons learned from the COVID-19 pandemic to the provision of health care in the future.

Regarding data, Bryant said it is clear that it is not possible to have quality care without addressing equity, which made it important to continue to track differential rates of COVID-19, health care utilization, and safety metrics by patient demographics. As Scott mentioned earlier, these clinical metrics should be the minimum of what is collected; there should be more focus on exploring the patient experience during the pandemic. Bryant also noted the need to move to a population health approach to understand who is in her institution's catchment area; they understood the need to reach out proactively, given that there are clear opportunities to follow up in vulnerable populations, and particularly those communities that are disproportionately affected by the pandemic.

She noted that, while aggregated and epidemiologic data can help guide policy efforts and community resource allocation, they must be used carefully at the individual, clinical level. "This parallels our efforts now to eliminate racialized medicine and avoid using race and ethnicity at the individual level to guide clinical care," said Bryant. As an example, when patients from hard-hit communities would show up in labor and test negative for COVID-19, comments would occasionally reflect surprise, with wonder about whether the tests represented false negatives. "We need to have ways of documenting these instances of racism, microaggression, and biases, and think about how we could aggregate these data and make sure we were not using these in a discriminatory fashion going forward," Bryant explained.

Communication was another point of emphasis in the best practices, particularly as it pertained to making information available in languages other than English and understanding the communication preferences of their

patients. Her institution created what were called multilingual care extenders, such as a Spanish language care group that was able to deliver care in the patients' primary language without needing to involve interpreter services, particularly during the more pressing times in the pandemic.

The SDOH were an important focus of care. Bryant noted that, while it is true that the social determinants are inequitably distributed because of structural racism and policies, it has been important during the pandemic to understand that the SDOH are a dynamic and sometimes situational construct. For example, food and housing insecurity became a far more important social determinant for many families who were not experiencing those issues before the pandemic. To help deal with those changing conditions, her institution addressed the need to expand health care teams during the pandemic and embed more behavioral health care specialists and community health navigators into care teams.

Another lesson learned during the pandemic was the need to focus on the positive and on community resilience. In that regard, she quoted Maureen Lichtveld, who wrote,

The root causes of poor disaster recovery can be stopped only by countering the devastating impacts of acute as well as chronic stressors. Disaster aid must prioritize those most vulnerable, regardless of race, ethnicity, income, and citizen status. One potentially daring but promising strategy is to elevate community resilience as an essential public health service and consequently integrate community resilience measures as performance benchmarks of federal, state, and local health agencies. (Lichtveld, 2018)

Bryant stated that the U.S. health care system has not yet integrated community resilience measures into its thinking about public health service. On a smaller scale, her institution did rely on communities to know their own selves and what was best for them and is now integrating community feedback into its plans for moving forward in this pandemic.

However, Bryant said that her institution did not always meet the metric of having patient-centric maternity care, particularly at the height of the pandemic. She credited the work of the Massachusetts COVID-19 Maternal Equity Coalition for elevating the voices of birthing people who gave birth during the pandemic. This steering committee held two town halls in June 2020 and 2021 to understand the challenges of birthing people during the pandemic and how health care was failing them. She cited a paper authored by several of the speakers at this workshop (Niles et al., 2020), one she said she clung to early on during the pandemic. It dismissed the idea that "the policies

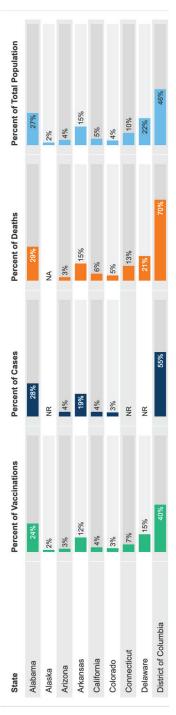
that uphold the human rights of birthing people and the policies that decrease risk of COVID-19 transmission are mutually exclusive" (Niles et al., 2020).

On the subject of how to achieve COVID-19 vaccine equity, Bryant noted that as of May 2021, there were clear inequities in the percentage of the population that had received at least one dose of a COVID-19 vaccine compared to the burden of disease (see Figure 13).<sup>31</sup> In the District of Columbia, for example, where 46 percent of the population is Black and where the Black community accounted for 55 percent of the cases and 70 percent of the deaths, only 40 percent of Black residents had received at least one dose of the vaccine. She recounted how the narrative early during the pandemic warned about low vaccine trust among Black Americans, and in fact, Kaiser Family Foundation surveys showed this to be the case well before a vaccine became available. What was missing from these findings, though, was that Black Americans were hesitant—they wanted to wait and see how the vaccine was working—not resistant. "It is not unreasonable for populations who have been historically marginalized to say that they are going to wait and see how things go," said Bryant. In fact, by February 23, 2021, large majorities of both Black and white seniors said they were eager to get vaccinated, though gaps still emerged among younger adults (see Figure 14).

Bryant concluded her remarks with a list of strategies that states and other jurisdictions are taking to improve vaccine access and prioritize vaccinations in communities that need it most:

- Using the CDC Social Vulnerability Index to allocate vaccines
- Prioritizing vaccination appointments by group or neighborhood
- Establishing call centers or texting options to facilitate access to those for home online sign-ups may not work well
- Locating vaccine clinics in underserved areas
- Collaborating with community-based organizations and federally qualified health centers (FQHCs)
- Conducting social media campaigns
- · Increasing awareness that the vaccine is available at no cost
- Clarifying that the vaccine can be given regardless of immigration status
- Publicly reporting vaccination data by race/ethnicity

<sup>&</sup>lt;sup>31</sup> The complete data set, updated regularly, is available at https://www.kff.org/coronavirus-covid-19/issue-brief/latest-data-on-covid-19-vaccinations-race-ethnicity (accessed August 14, 2021).



SOURCES: Workshop presentation by Bryant on June 7, 2021; https://www.kff.org/coronavirus-covid-19/issue-brief/latest-data-on-covid-19-FIGURE 13 Black people as a share of COVID-19 vaccinations, cases, deaths, and total population, May 24, 2021. vaccinations-race-ethnicity (accessed August 14, 2021).

Have you personally received at least one dose of the COVID-19 vaccine, or not? When an FDA authorized vaccine for COVID-19 is available to you for free, do you think you will...?

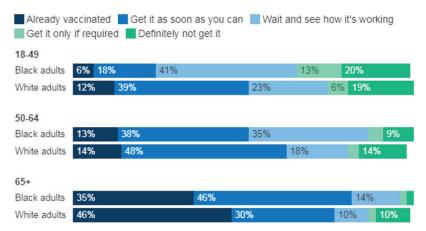


FIGURE 14 Large majorities of both Black and white seniors are eager to get vaccinated.

SOURCES: Workshop presentation by Bryant on June 7, 2021; https://www.kff.org/coronavirus-covid-19/poll-finding/kff-covid-19-vaccine-monitor-february-2021 (accessed August 14, 2021).

# Disconnects and Digital Divides: Black Women and Birthing People's Maternal Telehealth Experiences During the COVID-19 Pandemic<sup>32</sup>

Presented by Nia Mitchell, National Birth Equity Collaborative

In the panel's final presentation, Nia Mitchell discussed the results of a study that she, Ayanna Robinson, and Isabel Morgan conducted on telehealth during the COVID-19 pandemic. Specifically, the study explored the experiences of Black birth workers who provided telehealth care during the COVID-19 pandemic and the experiences of Black women and birthing individuals who received telehealth for maternal care during the COVID-19 pandemic. Mitchell pointed out that quality and respectful care throughout pregnancy and the postpartum period are critical to ensuring the health and well-being of individuals, families, and communities. She explained that the COVID-19

<sup>&</sup>lt;sup>32</sup> For further information about the findings of NBEC's study (publication forthcoming), find Nia Mitchell's complete remarks at the National Academies' workshop webpage: https://www.nationalacademies.org/event/06-07-2021/workshop-on-advancing-maternal-health-equity-and-reducing-maternal-mortality (accessed August 2, 2021).

pandemic and social-distancing restrictions have disrupted access to essential and wrap-around perinatal and postpartum care. This has increased the risk of adverse maternal and infant mortality among Black and Indigenous communities, as well as in other communities of color. Telehealth and other forms of remote services delivery are a promising means to improve equitable delivery of care to communities with the greatest need.

During August and September 2020, NBEC held three online listening sessions with Black women and birthing individuals, and three with birth workers. The listening sessions explored the following: the experiences of Black women and birthing individuals receiving maternity care via telehealth during the COVID-19 pandemic, benefits to and barriers/challenges with telehealth, and recommendations to improve the telehealth experiences of Black women and birthing individuals.

Mitchell listed the following seven themes identified from the listening sessions conducted with Black women and birthing individuals: (1) positive and negative experiences with prepandemic maternity care, (2) barriers/ challenges in receiving maternal care during the pandemic, (3) navigating social and emotional needs during the pandemic through self-empowerment and support, (4) dissatisfaction with medical care and seeking alternatives, (5) telehealth benefits, (6) telehealth perceptions and experiences, and (7) improving telehealth experiences. Mitchell also listed the following six themes identified from the listening sessions conducted with Black birth workers: (1) disruption to provision of care during the pandemic, (2) barriers to providing Black maternal health care before the pandemic, (3) observed inequities and discrimination in Black maternal health care, (4) experiences in providing telehealth, (5) barriers to and benefits of telehealth, and (6) recommendations to improve the telehealth experience of Black women and birthing individuals and Black birth workers.

The listening sessions also produced several recommendations to improve care provided to Black women and birthing people that fell into three categories: quality of care, decision making, and education.

#### Discussion

To start the discussion, Melissa Simon, posing a question from the audience, asked the speakers if any of the research they conducted or knew of unpacked or disaggregated Arab, Asian, Native Hawaiian, and Pacific Islander identity groups, given the socioeconomic and other inequities that exist among these ethnoracial subpopulations. Simon herself gave a quick answer, which is that this is a big challenge, just as it is for Latinx populations, Indigenous populations, and others. For example, Puerto Ricans in the United States face higher, inequitable maternal mortality rates, when compared to Mexicans

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such as herself. She added, it's important to unpack these data in order to do the groundwork to truly center care for birthing persons around their needs. Vedam remarked that her Giving Voice study is analyzing more detailed demographic information for Latinx participants and on specific identities the participants give themselves. She noted that "Asian" is another huge category that should not be used. The challenge in breaking down huge demographic categories is having a large enough population to get representative samples for small subpopulations of people.

Another audience member commented that Black birthing people in the United Kingdom, where midwifery is standard, have worse outcomes when compared to Black birthing people in the United States, and noted that the midwifery workforce in the United States is also less diverse than that of the United Kingdom; the audience member asked the panelists, many of whom recommended the expansion of midwifery in the United States as a solution, to comment on these assertions. Vedam responded that as a midwife of color, she was often sought out during her 25 years of practice in the United States because she was the only provider of color available, which points to the need to have more diversity across the board in the health care and birthing workforce. She also noted that midwifery care, from her analyses, appears to be more responsive in terms of autonomy, respect, and relationship-based care. She contended that that fact is not only the result of the concordance of the midwives, but is also the result of the model of care, the additional time afforded to the patient, and the approach to person-centered decision making and care. She recommended that this approach be expanded to all professions, but also recommended diversifying all workforces as well.

To conclude the session, Simon asked the speakers if they could provide one idea on what to expect moving forward, given what the community has learned during the pandemic. Gaw said she expects to see more attention paid to centering the voice of the patient in the clinical space. Mitchell said she wants the health care system to listen to and trust Black women, Black people, and the Black birth workers that care for them. She expects telehealth to find more use as a tool, but states that it will not fix poor quality of care or lack of access; if anything, telehealth, like the introduction of any new technology, has the potential to exacerbate existing inequities. For Bryant, the attention to the inequities affecting maternal health and reproductive populations has been more pronounced during COVID-19 and she said she hopes to keep that momentum going in terms of advocating for including pregnant and lactating individuals in studies of all types.

Simon then remarked that one important takeaway for her was that when communities and people come up with their own strategies to solve the health issue at hand, they generate the right answers. She concluded, "What I do not understand is why we as academics, health care providers, policy makers, and

public health professionals cannot always see that and cannot trust that the community knows the answer."

# MATERNAL HEALTH ISSUES RELATED TO THE FOURTH TRIMESTER

The final session of the workshop's first day discussed the postpartum period, the so-called fourth trimester during which time the individuals who give birth and their infants go through a period of great physical and emotional adjustment. This session featured four speakers—Alison Stuebe (University of North Carolina School of Medicine), Kanika Harris (Black Women's Health Imperative), Karen Tabb Dina (University of Illinois at Urbana-Champaign), and Kay Matthews (Shades of Blue Project)—and a discussion session moderated by Melissa Simon.

### Establishing the Fourth Trimester

Presented by Alison Stuebe, University of North Carolina School of Medicine

To open the session, Alison Stuebe commented on the fact that human babies appear to be born too soon compared to other primates who emerge from the womb considerably more developed and requiring a lower level of maternal care. One compelling theory for why human newborns are the way they are, said Stuebe quoting Trevathan and Rosenberg (2015) is that "there are advantages to having growth occur in the stimulating environment of the outside world and a dense social network." Stuebe elaborated, "Because our newborns come out primed to learn and to engage, they are able to develop more individuality and the social skills that are specific to the language and the interactions of the community around them."

Human newborns need many humans to help care for them, beyond the person who birthed them. In fact, anthropologists believe that one reason human newborns are so cute is to enlist other grownups to help care for them. However, while human evolution has created a dependence on the village, modern life has stripped the village away from newborn care. As Stuebe said, "if a mama and baby are alone, or even if there is a mama, a support person, and a baby, that is not enough to help women and their babies recover during this time period and help birthing people to thrive."

Steube said she wanted to frame the discussion around the question of what is needed as a culture and society to create an environment where infants and birthing people can thrive. She noted that the concept of the fourth trimester is not new, dating back to a 1975 paper that made the case that there

is a fourth trimester to pregnancy, and that society "neglects it at our peril," endangering mothers and their babies (Kitzinger, 1975). That paper argued that there is a transitional period of approximately 3 months, particularly marked after a first birth, during which many women are emotionally highly vulnerable; they may experience confusion and recurrent despair during this period, and anxiety and states of reactive depression are commonplace. "That was 46 years ago, and I would argue that we still have a lot of work to do to really create an environment where birthing people and infants can thrive," said Stuebe.

In addition to those maternal mental health experiences, the fourth trimester is a critical time for survival: more than half of pregnancy-related maternal deaths occur after delivery. Stuebe used an analogy to depict the lack of support currently offered to families during this period: She thinks of the baby as a piece of candy and the mother as the wrapper, and once the candy is out of the wrapper, the wrapper is cast aside. While the months leading up to birth feature weekly checkups, the standard of care in the United States until recently has been that birthing people do not return for a checkup until 6 weeks after giving birth. Although ACOG recommends having a checkup sooner than that, she noted that the insurance mechanism currently pays for only two visits for a birthing individual who had a cesarean delivery and just one visit after a vaginal birth. "It is very difficult to change a system of care when the framework and the insurance policies do not support providing that additional care," said Stuebe.

As Harris and Wolfe (2014) described, over the course of U.S. history, the fertility and childbearing of affluent, white birthing people has been valued over that of poor birthing people and birthing people of color. To drive this point home to new audiences, she points to a television show about a white family with 19 children that is planning for more. "When I pause to think how that would have been received by the American public if it were a family of color with 19 children, I think it becomes really apparent, the ways that we frame and value the reproduction of some and denigrate the reproduction of others," said Stuebe.

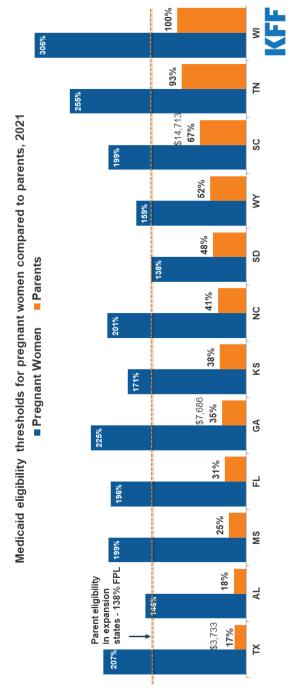
She said that this racist framing of reproduction also manifests in how U.S. society regards contraception. Dorothy Roberts argued in 1997 that, because the nation chooses not to spend money on social welfare programs or address the root causes of racism or poverty, preventing disadvantaged people from having children becomes viewed as a policy solution (Roberts, 1997). "I think as we think about goals for improving care in the fourth trimester," said Stuebe, "we need to be really thoughtful about where we put contraception in that model, because access to a full range of contraceptive options is absolutely necessary in order to enable birthing people to decide when they want to become pregnant again." At the same time, she added, coercion,

strong suggestion, or talking people into particular contraceptive methods becomes troubling when we think about the history of eugenics and birth control in this country and how it has been promoted and touted to particular populations.

Stuebe said that Medicare and Medicaid have also been a vehicle through which racism has affected reproductive outcomes. When Congress passed the law that established Medicare in 1965, it created Part C, which gave matching funds to states to provide medical care for low-income beneficiaries of the Aid to Families with Dependent Children program. This unusual pairing of a federal program for the elderly and a state program for low-income families came about, she said, because southern white senators were not going to vote for a program that mandated that they provide health care to communities of color. She said that President Johnson's move to leave up to the states the decision of whether and how Medicaid is disbursed amounted to a compromise with racism, and that this has curtailed the program's reach for decades (McGhee, 2021).

Stuebe then dove into the downstream effects of Medicaid being a staterun program, and how these are interrelated with racism and fourth trimester outcomes. Data show that most states in the southeast United States, where people of color account for the largest proportion of the population, have not implemented Medicaid expansion since the ACA was passed in 2010 (Artiga et al., 2019). To illustrate what this means for the fourth trimester, Stuebe noted that in North Carolina, a pregnant person can receive Medicaid insurance if their income is at 201 percent of the poverty line, but a single parent of two can only receive Medicaid if they are at 41 percent of the federal poverty line, or about \$750 per month (Artiga et al., 2019; see Figure 15). The situation is worse in Texas, where the cutoff for eligibility for Medicaid is 17 percent of the federal poverty line.

Systemic racism and stratified reproduction also affect the fourth trimester through parental leave policies that force too many people to go back to work within 10 days of giving birth. "Mothers are still figuring out how to breastfeed, babies are still figuring out who their mama is, and yet 23 percent of women are back at work," said Stuebe. "When we think about who the women are who do not have access to paid leave, they are those in the lowest income brackets and those with the least accumulated wealth." She suggested that this might be yet another consequence of racist redlining that prevented the grandparents of birthing people of color from being able to buy a home in the 1930s; in turn, this prevented wealth from being passed down across generations, ultimately resulting in a birthing person today being unable to take unpaid leave. "When we think about the kinds of policies we need to consider to truly achieve health equity, we need universal paid parental leave so that one's income and one's life history do not determine whether or not



For "Parents," eligibility limits calculated as a percent of the FPL and are calculated based on a family of three. In 2021, the FPL was \$21,960 for a FIGURE 15 Medicaid eligibility is much more restrictive for parents than pregnant women, particularly in states that have not expanded Medicaid. NOTES: For "Pregnant Women," reflects highest eligibility limit under Medicaid, Children's Insurance Health Program, or the unborn child option. family of three. Thresholds include the standard 5 percentage point of the FPL disregard. FPL = federal poverty line. SOURCES: Workshop presentation by Stuebe on June 7, 2021; Artiga et al., 2019.

one is able to bond with one's child," she said. She concurred with Burtle and Bezruchka (2016) that "the lack of policies substantially benefitting early life in the United States constitutes a grave social injustice." Those who are already the most disadvantaged in society bear the brunt of what Stuebe considers to be the consequences of the shortsighted and racist policies of paid leave in this country.

With respect to how the nation can improve the fourth trimester, Stuebe quoted the earlier presentation by birth activist Chanel Porchia-Albert, who says that every birthing person should be able to say, "I am seen, I am heard, I am loved." If that were the goal for the experience of maternity care, of birth care, and of care in the fourth trimester, Stuebe said, the nation would be closer to achieving equitable outcomes. In that regard, it is important to appreciate that true shared decision-making approaches consider there to be two experts: the patient and the provider. While providers are experts in clinical evidence, the patient and their family are experts in their experiences and values. In contrast, the historical paternalistic model of care has involved doctors telling patients what to do, with the patients responding, "yes ma'am" or "yes sir"; or the informative model, in which doctors ask a patient to make a choice without providing the information and context in which to make an informed decision. The goal, said Stuebe, should be to elicit values and preferences from the patient, and then share information and recommendations, and then reach a shared decision together. Along those lines, one thing she tells medical students and residents is that shared decision making does not mean that the patient must share the opinion of the physician or health care team at the end of the conversation, but rather that the patient is able to make a decision that aligns with their preferences and values.

Stuebe said she believes that it is critically important to fourth trimester outcomes that families be provided with comprehensive information. Toward that end, the Fourth Trimester Project at her institution has established two websites: newmomhealth.com and saludmadre.com, in order to provide honest, accurate, clear, and high-quality health information based on the latest science. These websites, she said, reflect and value the fact that birthing people are resilient, strong, and capable of making quality decisions for themselves and their families. They also reflect that communities and health systems should care for the birthing person, rather than demanding that they access care. She noted that both websites intentionally avoid telling new parents what to do, and instead offer advice on multiple options that they might find useful.

In closing, Stuebe reiterated a message repeated in several presentations at the workshop: The nation needs to aim higher than just achieving maternal and infant survival, and instead think about what it means today for birthing people and their newborns to thrive. Citing Jenifer Fahey's model for maternal





**FIGURE 16** The factors influencing maternal health in the year following birth. SOURCES: Workshop presentation by Stuebe on June 7, 2021; Fahey and Shenassa, 2013.

health in the year following birth (see Figure 16), Stuebe said that what birthing individuals need is to build core skills that help effectively mobilize social support, build self-efficacy, learn positive coping skills, and have realistic expectations (Fahey and Shenassa, 2013). "We need to design care that builds those skills and supports those capacities, and then we need to make sure there are the external resources to make that actually possible," said Stuebe. Regarding reproductive justice, she echoed the organization SisterSong's call to action to ensure that every individual has the "human right to maintain personal bodily autonomy, to have children or not, and to parent those children in safe and sustainable communities;"<sup>33</sup> she states that it should be ensured that society protects and values every parent and every child.

<sup>&</sup>lt;sup>33</sup> See https://www.sistersong.net/reproductive-justice (accessed August 17, 2021).

# Post-Birth Warning Signs and Exploring Concepts of Implicit Bias Among Obstetric Nurses

Presented by Kanika Harris, Black Women's Health Imperative

More than 60 percent of the deaths of Black mothers and birthing people occur during the postpartum period, with most occurring within 42 days after birth. At the same time, said Kanika Harris, CDC reports that 60 percent of pregnancy-related deaths are preventable (CDC, 2019). While she noted that there are many oversights that contribute to these deaths for all mothers, for Black mothers and birthing people in particular, racism, discrimination, and distrust from medical providers contributes significantly to the deaths during the postpartum period. In addition, studies have shown that experiences of racism dating back to a birthing person's own childhood, including traumatic birth experience, can contribute to postpartum mood disorders and postpartum depression (Kozhimannil et al., 2011).

With this context in mind, Harris and her colleagues conducted a study to understand the role of implicit bias among nurses. Before describing the results of the study, Harris briefly discussed the collaborative that came together to conduct it. The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN), in a program sponsored by Merck for Mothers,<sup>34</sup> invited her organization, the Black Women's Health Imperative, along with NBEC to develop some content for gaps AWHONN had in its post-birth warning signs program.<sup>35</sup> AWHONN, said Harris, wanted to highlight the crisis of racism and discrimination in maternal care as a significant contributor to maternal mortality. It engaged Harris and her colleagues to develop content specifically around the impact of bias, racism, and disrespectful care for maternal outcomes.

AWHONN's post-birth warning signs program has four goals: (1) to raise awareness and educate health care providers about key postpartum complications and warning signs; (2) to empower birthing people using a standardized parent education process to know the signs and get care quickly; (3) to ensure all health care providers are involved in educating women, birthing persons, and families; and (4) to ensure that all health care providers provide respectful care and act promptly on signs and symptoms of complications. The program addresses postpartum complications, including cardiac disease, pulmonary embolism, hypertensive disorders of pregnancy including preeclampsia and eclampsia, obstetric hemorrhage, venous thromboembolism, infection, and postpartum depression.

<sup>&</sup>lt;sup>34</sup> Merck for Mothers was also a sponsor for this workshop.

<sup>&</sup>lt;sup>35</sup> Additional information is available at www.awhonn.org/postbirth (accessed August 15, 2021).

One deliverable of the collaborative's work was a video titled *Knowledge to Action: Care Equity for Black Moms*. <sup>36</sup> It was originally intended to provide information for patients and consumers but, as Harris noted, ended up being aimed at providers. The video, she explained, reflects the lived experiences of Black mothers and nurses as a means of educating providers about inequities in birth and post-birth warning signs.

Turning to the study that she and her colleagues conducted, Harris described the theories that underlie their work, which sought to understand the collective experiences of mothers, Black nurses, and white nurses. They used standpoint theory, which among other concepts holds that an individual's own perspectives are shaped by their social and political experiences (Hartsock, 1983), and they also used critical race theory<sup>37</sup> as a framework. She explained that nurses and health care providers are often seen as the experts in terms of knowledge, skills, and evidence-based treatment, and that their position and authority are rarely questioned. That fact, along with standards of care and practice, can make it difficult for them to believe or admit that they are providing care that could be characterized as racially biased. Using standpoint theory allowed the researchers to change the hierarchy of knowledge for this type of research, and focus on the point of view of Black mothers. She noted that there is a gap in research that addresses health outcomes and their relationships to biases among nurses.

She and her colleagues looked at the dual perspective of 12 Black mothers and 12 labor and delivery nurses (see Table 4) to investigate the unique needs of Black mothers and how implicit bias among nurses operates. They conducted their research in the greater Atlanta and Washington, DC, metropolitan areas. They used an analytical methodology called "versus coding" to compare the varied perspectives of these two groups about the same phenomenon—childbirth—and conducted 90-minute race- and age-matched, in-depth interviews.

The main themes that emerged from the interviews with mothers and nurses were pain management and general treatment, racialized experiences, and health information communication. Comments about pain management

<sup>&</sup>lt;sup>36</sup> See https://www.awhonn.org/birthequity (accessed August 15, 2021).

<sup>&</sup>lt;sup>37</sup> Critical race theory is a body of legal scholarship that critically examines race and racism at the intersection of race and U.S. law. Scholars of critical race theory attempt to understand how victims of systemic racism are affected by cultural perceptions of race and how they are able to represent themselves to counter prejudice. Closely connected to such fields as philosophy, history, sociology, and law, critical race theory traces racism in America through the nation's legacy of slavery, the Civil Rights Movement, and recent events. See https://owl.purdue.edu/owl/subject\_specific\_writing/writing\_in\_literature/literary\_theory\_and\_schools\_of\_criticism/critical\_race\_theory.html (accessed August 18, 2021).

**TABLE 4** Descriptives for Mothers and Nurses

Descriptives for Mothers	Descriptives for Nurses		
Average age = 32	Six self-identified as white nurses and six self-identified as Black nurses		
42 percent were Medicaid beneficiaries	Average age = 40, with a range of 28–67		
46 percent had a doula present at birth	82 percent were registered nurses		
75 percent were married	Average length of practice = 9 years		
50 percent had advanced degrees	59 percent only worked in labor and delivery		
16 percent were high school graduates	25 percent were float nurses		
38 percent had a cesarean delivery	16 percent only worked in postpartum		
30 percent earned a salary of \$50,000 or less with two dependents			

SOURCE: Workshop presentation by Harris on June 8, 2021.

were not unexpected, said Harris, given that studies have documented that providers do not listen to pain complaints from Black individuals giving birth. Neither were remarks about disrespectful care. Though there were no questions about race, race kept coming up in explicit remarks from mothers, and in implicit comments from nurses. These comments came in the form of "dog whistling," which is coded language they used to describe their experience working with Black mothers versus others.

Harris then provided what she characterized as the most profound and jarring quotes. One 21-year-old mother said, "I said no, please stop, no, stop. I said no over and over again. I was assaulted against my will. I would give birth at a metro stop before I ever step foot back in that hospital." This quote captured a common theme among the younger mothers in the study: They felt that they were talked down to, that their ideas about their bodies were invalid, and that they had no autonomy over or knowledge about their birth process.

When one nurse, age 37, was asked about some of her lowest moments in practicing nursing, she began to admit experiences where she judged her patients based on their race, and how she felt that it was wrong. This nurse said that Black and white nurses talked about how they size up their patients with stereotypes and tropes before they even walk in the room. This nurse at one point said, "The situation that time—I mean, definitely [was] racial and [I] definitely judged someone based on they don't have as much money as you do, they are not as educated as you are. Thinking maybe they are not as smart as you are. Definitely those judgments."

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Speaking in broad terms, given that these results were still under review at the time of the workshop, Harris shared three needs that her study identified, which arose from the experiences of the Black mothers and the nurses:

- Survey tools to better capture and assess experiences of mothers and quality of care provided by nurses.
- Trainings to increase health communications among staff, including in-depth knowledge of racism and structural violence.
- Tools to better capture the perinatal and postpartum mental distress of Black birthing people.

She noted that one white nurse and one Black nurse specifically talked about the failure of implicit bias training to change the relationships they have with each other as staff. Black nurses talked about knowing and understanding implicit bias and trying to do their best for their patients, but felt that there is internal racism between them and the staff with which they work that also affects the care they can provide their patients. Black nurses talked, too, about losing autonomy around protecting and caring for their patients.

#### Perinatal Mental Health: The Role of the Fourth Trimester

Presented by Karen Tabb Dina, University of Illinois at Urbana-Champaign

Perinatal mental health disorders are the leading cause of maternal morbidity and mortality in the first 12 months postpartum, said Karen Tabb Dina. In fact, up to 20 percent of birthing people will experience a perinatal mental health problem during or after the time of giving birth. Perinatal depression, she said, affects 12–15 percent of all birthing people, though fewer than 30–50 percent will receive treatment. Perinatal anxiety affects about 15 percent of birthing people, and suicidal ideation affects 2–5 percent of all birthing people and suicide is a leading cause of maternal mortality. Bipolar disorder affects from 0.5–2 percent of birthing people and can have serious consequences, particularly when psychosis is involved. While perinatal psychosis receives a great deal of attention in the media, it is extremely rare, affecting one or two birthing persons per 1,000.

Black and white women living in rural settings, she said, are more likely to experience maternal mortality, and face 30–50 percent more risk compared to urban women for maternal mortality (Ely et al., 2017; NACRHHS, 2020; Warren, 2020), and increased risk for perinatal depression (Nidey et al., 2020). Birthing people living in rural settings are also at greater risk for experiencing

perinatal depression. This is in part due to the shortage of mental health and rural health facilities across the nation, which leads to delayed identification or an inability to access care.

Tabb Dina noted that one of the alarming trends she has seen over the past decade is in disparities in maternal mental health related to race, ethnicity, and perinatal mental health (Admon et al., 2021b; Gavin et al., 2011a,b; Mukherjee et al., 2016; Tabb et al., 2020). Racial and ethnic minority women are more likely to express symptoms of depressive disorders, but are less likely to have a medical diagnosis in their chart, she said. There are also significant disparities in perinatal suicidality among Black and Asian birthing people after giving birth (Tabb et al., 2020). The trends regarding suicidal ideations and self-harm are particularly alarming, said Tabb Dina, with non-Hispanic Black childbearing individuals and individuals with lower education levels being at particular risk (Admon et al., 2021a).

The COVID-19 pandemic has exacerbated the maternal mental health crisis. Studies from across the globe show that perinatal depression (Davenport et al., 2020) and psychological distress (Ostacoli et al., 2020) are now affecting close to one in two birthing people. Pandemic-related stress—the distress of being pregnant during the pandemic and fear of passing the virus to the unborn child—is affecting upward of one in three women (Preis et al., 2020), and anxiety is at unprecedented levels, affecting nearly three-quarters of all birthing people (Davenport et al., 2020). Untreated perinatal depression, said Tabb Dina, brings with it both neonatal and obstetric risks, and it also affects infants and other children in the household (Bonari et al., 2004; Gentile and Fusco, 2017; Kendig et al., 2017; Tareen and Tandon, 2018). The cost of untreated perinatal depression is estimated to be \$14 billion per year (Luca et al., 2020).

Fortunately, said Tabb Dina, there are promising research-informed solutions, and even technology companies are stepping up to address perinatal depression. For example, in early 2021, Google searches for information on postpartum depression began directing users to the Edinburgh postpartum depression screening that they can take themselves.<sup>38</sup> She noted that 17 states now have access programs modeled after the Massachusetts Child Psychiatry Access Program for Moms. Research shows that collaborative models of care are effective for helping women of racial and ethnic minority populations, women living in rural areas, and women who are pregnant and not yet postpartum (Hu et al., 2020). In 2019, the United States Preventive Services Task Force (USPFTF) issued a recommendation that there are brief, problem-based

<sup>&</sup>lt;sup>38</sup> See https://landing.google.com/screener/postpartum-depression (accessed August 15, 2021).

therapies that in just two sessions can be effective in preventing perinatal depression (O'Connor et al., 2019).

If the goal is to have a universal approach to address the alarming rise in maternal mental health problems, screening is the way to go, said Tabb Dina. "If we screen all women universally, we can tap into what those needs are universally," she said, noting that Illinois and several other states now enforce mandates to screen all birthing persons. She and her collaborators have looked at the comparative effectiveness of depression screening in clinics, and their early results show that immediate provider feedback is the most important factor for success. "When people complete the depression screen, they would like a health care provider to tell them how they did so that they can make plans that better suit their needs," she explained.

Going forward, Tabb Dina said, the key points of emphasis should be on universal approaches such as universal perinatal depression screening using validated tools. These offer promise for the fourth trimester. This is especially important given that the pandemic has exacerbated mental health challenges for birthing populations. She recommended tools such as the Patient Health Questionnaire, which can be used with the seven-question general anxiety questionnaire. Tabb Dina also called for clinical research innovation that uses the voice of the patient, and that involves community partners to drive studies. This will enable the research to address the needs of the individuals living with the experience of perinatal depression or anxiety. "If we cannot address the needs of individuals living with the experience, we are not going to come up with long-term solutions that actually tap into disparities," she said in closing.

## Improving Maternal Mental Health Outcomes for Women of Color

Presented by Kay Matthews, Shades of Blue Project

In the day's final presentation, Kay Matthews discussed the I.N.S.P.I.R.E. Journal Method. This, she explained, is a community-based organization's approach to improving maternal mental health outcomes for women of color, <sup>39</sup> and shifting the culture around maternal mental health. Noting that her colleagues at the workshop had highlighted many of the troubling statistics around racial inequities already, she shared that one in four women of color will experience postpartum depression, compared to one in seven white women. Moreover, women of color are four times more likely to have their symptoms go undiagnosed.

<sup>&</sup>lt;sup>39</sup> The work of Matthews and her team was conducted with individuals who identify as women, so this section will use that word rather than "birthing persons."

When she and her colleagues ask their clients what barriers they face to accessing mental health care, the answers include statements such as, "What will my family say?," "My doctor doesn't listen to me," "My mental health is not that important," "It's time to turn my attention to my baby's care, not mine," "I've heard maternal mental health services referred to as a luxury," and "Last time I asked for help I thought they would take my baby away from me." These answers, said Matthews, point to barriers such as the stigma associated with mental health as a whole, let alone when there is a child involved. The fear of losing their child is a big concern among parents of color with a newborn child. Matthews said that her organization centers their direct services around these, the direct experiences and desires of their clients. When creating the I.N.S.P.I.R.E. method, Matthews said she was motivated by the fact that traditional approaches to addressing postpartum depression among women of color have proven to be lacking, given the disparities that persist in outcomes.

Matthews and her organization conducted a study to examine the impact of the I.N.S.P.I.R.E. method. They created what she calls a "nontraditional approach" to addressing postpartum depression in women of color. She highlights that it comes from the community. The method is a journaling approach, in which participants attend a 1-hour session each week for 6 weeks. In each session, they discuss a section of the journal, each of which centers around one of the letters in I.N.S.P.I.R.E. Matthews said that each lesson helps the participants to identify what they can do on a daily basis to take control of what is happening, to advocate for themselves to get into a recovery state of mind. I.N.S.P.I.R.E., in this case, is an acronym for Initiate change, Nourishment and exercise, Spirituality and prayer, Patience, Involve others, Rest and relaxation, and Each day is a new day to start again. She noted that each of these phrases requires thoughtfulness on the part of the participant as well as instruction and help from staff. She emphasized that the entire method is centered around "guidance," but recognizes that no individuals are the same, and does not prescribe specific instructions or shame participants.

She then described the various phrases in more depth. Matthews said that initiating a change process is not something most people know how to do automatically, but once the client identifies what needs to change, staff can point them in a direction that can produce change.

Spirituality and religion, she noted, are important in the Black community and can help with the healing process when connected to mental health. Perhaps the hardest thing to get across, though, is the need to involve others, said Matthews. "We talk through what that looks and feel[s] like because mental health is tied to feelings. 'Involve others' is about showing how to ask people for help, the help they need so that they do not have to suffer in silence," she explained. The rest and relaxation component, said Matthews, involves teaching individuals what it feels like to relax and rest and to get

the respect they need from others in their family so that they can take the 15 minutes they need to rest and relax. The last piece, each day is a new day to start again, focuses on getting rid of the blame that too many new mothers heap on themselves for feeling depressed or anxious. This piece focuses on removing the "I failed today" guilt response to skipping a meal or missing their other child's school recital, for example. Matthews said that she has learned that getting people into a recovery state of mind allows them to understand that they could go 2 or 3 years without any incidences or occurrences, have a bad day and feel they made a mistake, but then move forward the next day. "This is a day-to-day process," she emphasized.

The study that Matthews and her team conducted over a 6-week period involved assigning three groups to use the I.N.S.P.I.R.E. journaling method, and having three groups that did not. Participants were screened before and after the 6 weeks using both the Patient Health Questionnaire-9 (PHQ-9) scale and a culturally specific normed stress scale, created by Dr. Fleda Mask Jackson. Participants also self-reported outcomes. The team found that the participants who used the I.N.S.P.I.R.E. method were able to increase their coping skills and distress tolerance. They also expressed an increased willingness to engage in maternal mental health counseling and a decreased stigma against seeking treatment.

Matthews explained that increased coping skills and distress tolerance helped the participants deal with issues more effectively on a daily basis, which helped break the maternal mental health depression cycle. Developing a willingness to seek counseling services was a significant improvement that required the participants to understand how effective counseling services can be during maternal mental health complications. By decreasing the stigma associated with maternal mental health challenges, the I.N.S.P.I.R.E. method normalized getting help in the fourth trimester and helped the participants understand that having a mental health issue postpartum has no bearing on who they are or who they hope to be.

Matthews and her team found that three important components to successfully implementing the I.N.S.P.I.R.E. method were for facilitators to focus on acknowledgment, respect, and support. "These are mandatory, not optional, and they should be given to every client and every patient you encounter," said Matthews.

In conclusion, said Matthews, she considers I.N.S.P.I.R.E. to be a therapeutic model that is proven to help reduce the statistics around postpartum depression in women of color. It has proven to be a cost-effective approach, too. Going forward, the plan is for the Shades of Blue Project to open a Black maternal mental health resource center and community clinic in later in 2021, where they will continue offering training on the I.N.S.P.I.R.E. method. She noted that Black maternal mental health week is scheduled for July 19–25. She

also pointed out that this is a collective effort, which it needs to be given how maternal mental health in women of color has been pushed to the wayside. She called for a cultural shift that views the fourth trimester as the "next phase of delivery," to help underscore its importance.

#### Discussion

The first question Simon posed to the speakers asked them how to address the perception, arising either out of ignorance or intolerance, that engaging in yoga or other forms of mindfulness practice is "devil's work" or a "gateway into Satan's garden." Matthews said it requires having hard conversations that bring the question of religion and spirituality into the discussion of mental health. Harris agreed and added that this is about cultural perspectives and learning about how to work within people's cultural paradigms. "It is important to recognize as well, that the things that we are saying today that are mainstream may not necessarily fit into someone's cultural paradigm, and we also have to look for things that work for them, and work within their framework as well," said Harris. Simon noted the importance of listening, centering the person, and "meeting them where they are." She also commented on the overarching importance of unlearning misguided, racist behaviors and beliefs. Stuebe pointed out that there is a field of de-implementation science, focused on this. She said she thinks the I.N.S.P.I.R.E. method is brilliant and hoped that the next step will be to figure out what its essential ingredients are so that it can be used for people in other contexts.

Tabb Dina commented that in this discussion, she saw many of the themes of the day running together: unlearning and "decolonizing" our minds, providing respectful care, focusing on listening, and centering community and patients.

The next questioner asked about concordance of providers, team members, and patients, and the impact that this can have on maternal health outcomes. Tabb Dina said she has a "knee-jerk reaction" to the question of racial matching as the only solution to addressing disparities in health care. She acknowledged, on the one hand, that there is a level of comfort and acceptability for a patient when their provider looks like them. On the other hand, she feels that all providers agree to the Hippocratic oath to "do no harm." She feels that concordance is not a silver bullet solution by itself; that rather, every provider must first start by respecting the client in front of them as a human. Both Tabb Dina and Simon said that it is imperative to improve the pathways and pipelines to increase the number of people of color in the health care workforce to be more reflective of the population, but that is going to take time and the situation today is dire. When Simon then asked what short-term steps there may be, in the meantime, Harris and Matthews responded.

Harris expressed that it is not sufficient to have a provider simply claim to see a patient as "another human," but that they must understand the layered history that people of color have experienced in this country. Matthews said that acknowledgment is critical because it leads to respect that then leads to the support and care a person needs.

McLemore also commented on the complexities of concordance. She expressed the importance of recognizing that community members, such as formerly incarcerated persons trained as doulas, do have the capacity to provide quality care. She noted that there should be a focus on developing a skillset through training. Similarly, she said she feels that cultural humility can be trained as well. She emphasized that in thinking about concordance, she does not want to deny the humanity of people who want to provide care whose identities may not align with those of their patients. Rather, the important thing is to curate a space to ensure that people with lived experience have the opportunity to become a part of the future workforce, and that their contributions are valued.

Stuebe said she likes to address the power dynamic that exists in a room by asking each patient, "What is going well?" This, she said, is a much more joyful way to start a conversation. She also thinks it is very important to ask the individual "What's your understanding of what's going on?" in order to elicit how they understand their medical situation. "That gives me a chance to see what the patient understands, and usually I'm deeply impressed with the patient, which then validates her understanding of what is going on," she said. When she makes a recommendation, she tells her patients that that is coming from her experience with other patients; she then asks them whether the recommendation makes sense for their own bodies, being sure to validate the patient's expertise and lived experience. She tells patients, "You have lived in your body your entire life. How do you think this might work for you?" Lastly, she does not shy away from naming racial health inequities when a patient is concerned, and discusses the steps being taken to ensure that they are kept safe.

Another audience member asked what can be done to ensure that USPSTF's recommendations on postpartum screening and prevention can be implemented within our current system. Tabb Dina replied that collaborative care works and that one consultation center can help an entire state, and saves cost at the same time. Simon, who serves on the task force, stressed that USPSTF's decision to issue a recommendation statement for collaborative care helped to push the growth of that framing; she noted that more such recommendations could be beneficial for accelerating responses to maternal health crises.

Another questioner asked, "Considering that it is being made evident via research and data analysis that the period of concern is 1 year after birth,

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how do we push maternal mortality and mental health state policy agendas past 60 days?" Tabb Dina said that extending Medicaid into the postpartum period opens a window of opportunity for people to get care, though getting people in to see providers is still something that needs work. Currently, half of the births in the country are supported by Medicaid, but this coverage is dropped shortly after delivery. Illinois recently extended Medicaid eligibility through the end of the first year of life, and Florida's governor expressed interest in doing the same.

Finally, several of the speakers then noted the importance of extending care to a birthing person's support people, and even the health care team, all of whom play important roles in helping new mothers and their infants to thrive.

## STATE EFFORTS TO REDESIGN MATERNAL HEALTH CARE

Day two of the workshop addressed ongoing efforts at the state, local, and federal levels to address the maternal health equity crisis. Throughout the day, the speakers discussed promising approaches and interventions to advance maternal health equity and the challenges and successes they have experienced along the way. The day ended with a session about future directions for research funding.

The day's first session featured three presentations on efforts to restructure health care delivery systems at the state level in order to better address the needs of birthing persons. The three speakers were Kathryn Menard (University of North Carolina), Chanel Porchia-Albert (Ancient Song Doula Services), and Zsakeba Henderson (March of Dimes).

### North Carolina's Pregnancy Medical Home

Presented by Kathryn Menard, University of North Carolina

North Carolina, explained Kathryn Menard, encompasses some 50,000 square miles, spanning the Outer Banks to the Blue Ridge and Smoky Mountains, with major metropolitan areas and expansive farmland. The state has approximately 10 million residents, and most counties have a population density of less than 250 residents per square mile. Menard noted that North Carolina has about 120,000 births annually, with 50–55 percent funded by Medicaid. There is a fair distribution of level-three and level-four birth hospitals across the state (see Figure 17).

Relative to the United States, the North Carolina population includes a slightly larger proportion of people of color. In 2019, 35 percent of birthing people with Medicaid identified as non-Hispanic Black, 23 percent as



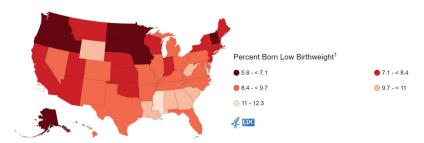
**FIGURE 17** North Carolina's birth hospitals and urban and rural counties, 2019. SOURCES: Workshop presentation by Menard on June 8, 2021; NC State Center for Health Statistics, Birth Certificate Data.

Hispanic, and 1 percent as Native American. Medicaid pays for approximately 70 percent of births to Black persons in North Carolina, said Menard. She noted that North Carolina's maternal mortality rates and racial disparities are similar to those seen at a national level, though she noted that the maternal mortality rate among those identified as Black is lower in North Carolina than in most other southeastern states.

The state has a long-standing maternal mortality review process that reports on pregnancy-related deaths. The data reveal a decline in the Black population's maternal mortality rate, from 55.5 deaths per 100,000 live births in the 2001-2004 reporting period to 27.7 in the 2013-2016 reporting period (Lopez-Littleton and Sampson, 2020). Over the same time spans, the maternal mortality rate among white birthing people increased from 9.2 deaths per 100,000 live births to 15.9 deaths per 100,000 live births (CDC, 2020). Nonetheless, said Menard, the disparities remain profound, with a 1.7 Black-to-white ratio of severe morbidity in birthing people. She noted, too, that in 2019, North Carolina had the 10th highest low-birthweight rate in the nation. She explained that a baby is considered low birthweight when they are born weighing less than 5 pounds 8 ounces, and that this is a problem that plagues southeastern states (see Figure 18). Furthermore, North Carolinian babies born to Black birthing people were twice as likely to be of low birthweight than babies born to white birthing people; babies born to Native American birthing people were 1.5 times more likely to be of low birthweight. Rates among births to Hispanic individuals were similar to those of the white population.

With that as context, Menard described North Carolina's Pregnancy Medical Home, which the state established in 2011 in partnership with North





**FIGURE 18** Percentage of births born weighing less than 5 pounds 8 ounces, by state, 2019.

NOTE: <sup>1</sup> Babies born weighing less than 2,500 grams or 5 pounds 8 ounces. SOURCES: Workshop presentation by Menard on June 8, 2021; Division of Vital Statistics, NCHS, CDC, Department of Health and Human Services.

Carolina Medicaid, Community Care of North Carolina, and the North Carolina Department of Public Health. The aims of this public—private partnership were to improve quality of care for pregnant Medicaid beneficiaries, improve birth outcomes, and reduce health care costs for the Medicaid population. A primary focus of the Pregnancy Medical Home program is to prevent preterm births, and there were two main strategies to addressing this: engaging maternity care providers serving the Medicaid population in quality-improvement efforts, and introducing community-based care management that targets those at greatest risk for preterm birth.

The care management model that North Carolina developed was inspired, in part, by previous work done in South Carolina where a region-based care management intervention was associated with a significant reduction in very low birthweight, said Menard. The core components of North Carolina's population-based, enhanced prenatal care model include

- a large network of obstetrics providers to increase access to care;
- local clinical leadership with regionally based teams that offer provider support, education, and technical assistance;
- Pregnancy Medical Home care pathways that guide best practices reflecting the most current evidence base;
- standardized, statewide risk screening;
- robust informatics providing process and outcome data at the state, regional, county, and practice levels; and
- community-based care coordination managed by nurses and social workers.

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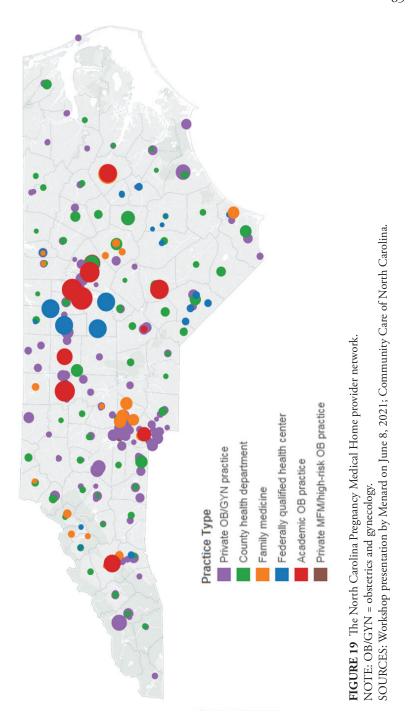
Menard said that an expansive and diverse network helps to ensure access to care—it includes more than 2,600 providers at 490 enrolled practice locations, accounting for more than 90 percent of the maternity care for Medicaid beneficiaries (see Figure 19). The program is organized into 14 regional networks, each of which has an obstetrics nurse coordinator and an obstetrician champion who is a respected, public health—minded medical community leader at a major academic center, large health system, public health department, or independent community obstetrics-gynecology practice. Together, the two regional leaders provide their respective Pregnancy Medical Home communities with consistent messages, offer support related to clinical initiatives and program performance expectations, and share practice-level data for use in quality improvement. Most importantly, said Menard, they listen to the needs and concerns of the local providers and bring feedback to the state level, where program and policy changes can be addressed.

As those needs arise, she noted, the clinical leadership collaborates to develop evidence-based clinical pathways, with supporting materials and resources for quality improvement. The topics that have arisen have included

- hypertensive disorders of pregnancy
- perinatal tobacco use
- substance use in pregnancy
- postpartum care and the transition to well woman or primary care for the birthing person
- progesterone treatment and cervical length screening
- obesity in pregnancy
- reproductive life planning/postpartum contraception
- multifetal gestation
- COVID-19 care and resources

In the Pregnancy Medical Home program, Medicaid beneficiaries receive a standardized risk assessment during their first prenatal visit. The screening tool captures medical, obstetric, and psychosocial factors that are associated with preterm birth, such as tobacco use, food insecurity, and housing instability. Menard explained that these factors to a large extent mirror those associated with maternal morbidity and mortality. In practice, she added, nearly 80 percent of patients who receive care in a Pregnancy Medical Home are assessed using the risk screening tool. These data are used to guide prioritization of care management services.

To support the quality improvement work of the Pregnancy Medical Home program, Community Care of North Carolina created a robust, statewide, population-based clinical informatics resource that illustrates individual



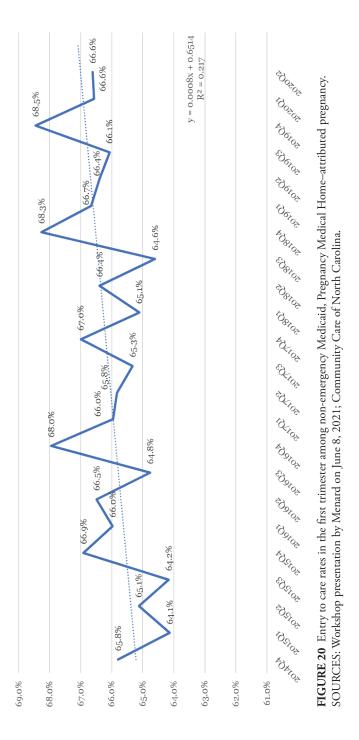
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and population needs. It uses risk-screening data linked to Medicaid claims, care management data, and birth certificate data to illustrate process measures and outcomes. From these data, the program derives quarterly metrics to share with the program's practices, county-based pregnancy care management programs, regional networks, and Medicaid program leadership. Measurement of clinical quality, said Menard, reflects program priorities and includes metrics such as use of the risk-screening tool, timeliness of entry to prenatal care and postpartum care, contraceptive choice, provision of tobacco cessation counseling, and mode of delivery.

These informatics resources allow for practices to see how their performance compares to that of their peers, and for a leadership team to identify where to focus resources for greatest impact in improvement. Program staff can also look at individual metrics over time and at the state, county, and practice levels. For example, one metric shows the trend over time of entry into prenatal care during the first trimester, one of the several collaborative quality-improvement initiatives with which practices have chosen to engage (see Figure 20). Another metric shows a strong, positive trend in unintended pregnancies, as recorded on the risk screen at the time of the initial screening (see Figure 21). Menard said that since the program's inception in 2010, various improvement initiatives have contributed to this encouraging trend. She credits the work of the care managers who engage with birthing people to remove barriers to adherence to the postpartum visit, discuss the health benefits of birth spacing, review contraceptive choices, and inform patients of the availability of family planning services.

All of these data can be stratified by race and ethnicity to identify meaningful differences in trends. For example, risk-screening rates in the Native American population in North Carolina consistently exceed the benchmark of 80 percent, higher than any other subgroup. "I believe this high performance is attributable to the effectiveness of the culturally matched Native American care managers in certain counties of North Carolina," said Menard.

Another important component of the Pregnancy Medical Home program is the community-based care management. All patients undergo the initial screening, and this component of the program focuses on those found to be at the highest risk for preterm birth. Menard explained that nurses and social workers in local health departments provide assessment, education, advocacy, referral, and monitoring. Importantly, she said, the care managers are from the community and know the local culture and available resources. The program encourages the care managers to have face-to-face contact with their clients, and many of these encounters occur in the provider's office. This clinical/public health partnership is designed to ensure optimal communication and to identify barriers to care. The care managers help ensure that the pregnant person's preferences and needs are heard and met.



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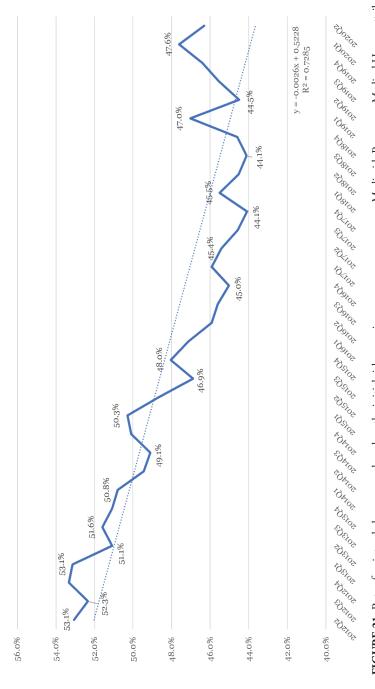


FIGURE 21 Rate of unintended pregnancy based on the initial risk screening among non-emergency Medicaid, Pregnancy Medical Home-attrib-SOURCES: Workshop presentation by Menard on June 8, 2021; Community Care of North Carolina. uted pregnancy.

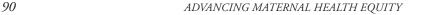
In the initial years of the program, the risk-screening tool identified 70 percent of the population as high risk for preterm birth and low birthweight, but risk screening did not predict which patients would benefit most from care management. Care management resources were stretched thin. To address this issue, Community Care of North Carolina used Pregnancy Medical Home program data to identify the risk factors that care management could impact the most, leading to the creation of a Maternal-Infant Impactability<sup>TM</sup> score. In developing the scoring system, greater weight was given to those factors for which high-intensity care management was associated with lower rates of preterm birth.

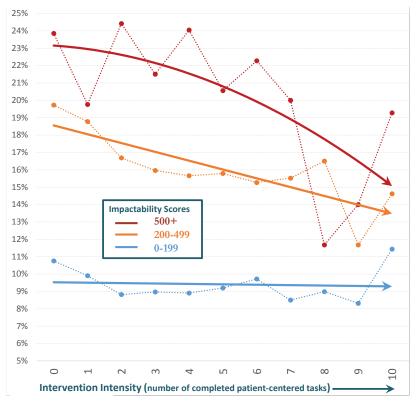
The Impactability<sup>TM</sup> score, developed from the risk-screening forms, is divided into high, medium, and low strata that indicate a birthing person's risk. It also explains the frequency and type of expected care management contact that should be provided. The tool has been validated for identifying those most likely to benefit from such care. For patients at intermediate and high-risk strata, benefit was seen at five completed patient-centered tasks through the program; face-to-face encounters provided greater benefit than telephone visits (see Figure 22). Menard expressed that it helped them to focus resources in a more equitable way, with those patients who were most likely to benefit.

Implementing this system produced marked reductions in low-birth-weight births in both Black and white high-risk groups that received five face-to-face encounters with a care manager, compared to those who did not receive the intervention. However, Menard noted that despite the intervention, Black birthing people still delivered low-birthweight infants at higher rates than white birthing people.

Reflecting on 10 years of experience with this program, Menard highlighted features that she believes have the greatest potential to advance maternal health and equity and reduce maternal mortality:

- Standardized risk assessments for every pregnant patient, regardless
  of color, preferred language, education, or socioeconomic status, can
  minimize bias and lead to more equitable and appropriate identification
  of need. They can also improve connection with local resources and
  inform an appropriate care plan.
- Practice-level process and outcome data, stratified by race/ethnicity, can reveal specific and actionable differences, stimulate detailed gap analyses, and enable data-informed rapid-cycle quality improvement.
- A locally designed, patient-centered, team-based model supports the unique needs, culture, and values of the individual birthing person within their community.





**FIGURE 22** Impactability<sup>™</sup> score for pregnant people for a patient-centered task. SOURCES: Workshop presentation by Menard on June 8, 2021; Community Care of North Carolina.

- Having care managers embedded in practices as part of the care team
  and who are community members (often race concordant) can promote
  a deeper understanding of the pregnant person's needs, preferences, and
  barriers to care. The patient may experience a greater sense of trust when
  they feel part of a well-integrated team.
- Data sharing and collaborative learning across the provider community can promote provider engagement and accountability in this work.
- Practice support for program implementation and quality improvement can make a significant difference in the lives of birthing people.
- System-level monitoring of access, program performance, and quality
  can identify areas of greatest need that then allow limited resources to
  be focused on meeting those needs.

Menard noted that North Carolina, like many states, has done a good job with state-level quality collaborative improvement efforts that focus on inpatient care. Implementing consistent protocols within hospitals for management of conditions such as obstetric hemorrhage and severe hypertension have been shown to advance equity, though important disparities exist. She added that in obstetrics, it is unusual to find effective infrastructure for broad-scale quality improvement in the community and outpatient settings. She noted, too, that the leading cause of pregnancy-related death in Black birthing people is cardiovascular disease, which cannot be addressed by hospital-based quality-improvement efforts alone. "A structure for implementation at scale in the outpatient setting is needed," said Menard.

## Support Community-Based Doula Organizations Working Toward Bridging Racial Inequities in Maternal Mortality Rates

Presented by Chanel Porchia-Albert, Ancient Song Doula Services

Chanel Porchia-Albert presented on community-based and policy-level approaches to improving doula access. At Ancient Song Doula Services, she said, the focus is on the whole, not the parts. Her organization uses community advocacy and reproductive justice approaches to address challenges affecting birthing people in New York City and northern New Jersey, with a special focus on birthing people of color. Specifically, they seek to address maternal mortality and morbidity through training and policy, and by offering direct services to the community for pregnant and parenting people. 40

Porchia-Albert said her organization advocates for policy reform through campaigns for equity in maternal health. In particular, they seek to focus on addressing racism and implicit bias within the maternal health and reproductive health structure. "As an individual doula coming into a space, I can only do so much on an interpersonal level, but what does it mean for us to really enact systemic change throughout the health care system?" she asked. One activity the organization undertakes each year, to this end, is their annual Decolonize Birth conference, which brings together policy makers, researchers, data researchers, and an everyday individual parent to be able to inform the ways that Ancient Song Doula Services supports individuals throughout their reproductive life course.

<sup>&</sup>lt;sup>40</sup> See https://www.ancientsongdoulaservices.com/our-focus (accessed August 17, 2021) for more information.

Her organization also emphasizes the importance of education, and holds educational workshops, conferences, and trainings. They focus on both providing information to birthing people to give them the tools they need to empower themselves to make informed decisions about their reproductive health choices, as well as on giving providers and institutions information to incorporate justice into their institutional framework.

The process Porchia-Albert uses is one of understanding, engaging in the legislative process, getting the community to act, and listening to her stake-holders. "At Ancient Song, we definitely believe that community is one of our largest and most prominent stakeholders, and that we are not there to dictate to them from a top-down approach of what it looks like to initiate care," she said. "We understand that care is fluid and that we must continuously be in community with community members to understand how that flow should happen."

The legislative process, said Porchia-Albert, starts with ground-up education; they take a community-based, grass roots approach to legislative policy, and are sure to include all intergenerational members of the community as stakeholders. These efforts, she explained, are not focused on one specific group because from the time someone is born, they are being affected by policies that will affect their reproductive life course and choices. "In understanding that, we understand that our legislative processes then must be intergenerational, and doula access must also be intergenerational," she said.

In addition to their direct service work, Ancient Song Doula Services has created an integrated community-based doula model at a major hospital in New York City, Elmhurst Hospital. With this model, they sought to center community input to inform delivery of care. All providers throughout the hospital are being trained in an integrative reproductive justice framework and how to work with doulas.

On the policy level, Ancient Song Doula Services has been working with New York State assembly members on two bills: A.364B<sup>41</sup> and S.3344B.<sup>42</sup> These would require that every doula enrolled in the Medicaid reimbursement program be certified by a health commissioner, a process that requires a \$40 application, completion of certification requirements that the state would specify, and passing a state-defined "good moral character" background check. Almost immediately, she and her team saw unintended consequences regarding the access to doulas and a doula's ability to provide needed services. To

<sup>&</sup>lt;sup>41</sup> For more information about New York A.364B, relating to the professional certification of doulas, see https://www.nysenate.gov/legislation/bills/2019/a364 (accessed August 18, 2021).

<sup>&</sup>lt;sup>42</sup> For more information about New York S.3344B, relating to the professional certification of doulas, see https://www.nysenate.gov/legislation/bills/2019/s3344 (accessed August 18, 2021).

start, the registration fee could be an impediment for doulas who may be on Medicaid themselves, seeking to support their communities. A certification specified by the state would require taking an exam that may be redundant in light of the fact that doulas already complete a defined curriculum. Lastly, the background check would disqualify anyone who was previously incarcerated, could curtail workforce development, and might deprive individuals of an opportunity and the resources to connect within their communities and give back in a meaningful way.

Her organization's approach to addressing these issues was to host community listening sessions across the state in partnership with other community-based organizations. These sessions were intended to help her organization understand both how people in rural and urban areas of the state accessed doula care, and to help doulas and other community members to understand how the legislative process works so they could guide the solution. "We understand that this is not just about having doula access on an interpersonal level, but also about access on a policy level and understanding the unintentional consequences of that," said Porchia-Albert. She noted that many people in the community were unaware of these bills until their passage, despite the legislation's direct impact on community-based doulas and the families and communities they serve.

Her organization has now started the #BeyondBirthWork campaign to support community-based doulas who go beyond the interpersonal relationships they develop to provide holistic, culturally relevant care to birthing people of color and low-income birthing people who would not otherwise be able to afford care. The campaign's goal is to mobilize the community to address the problems with these bills that would restrict doula care and reduce access to marginalized communities. Porchia-Albert said she would like to see legislation that would define doulas and their scope of action—rather than creating a new entity called a "certified doula"—and instead clarify to whom the bill applies and distinguish between state-certified doulas and doulas certified elsewhere. In addition, she would like the state to offer opportunities for prospective doulas to train with established certifying bodies instead of collecting fees; the state might also fund Black women-led doula organizations rather than creating a state-controlled program. Finally, she wants to see the state focus on ending structural racism in medicine instead of regulating doulas. She said that this process requires a focus on institutional processes, and that these should be centered around equity and accountability.

Porchia-Albert said that the COVID-19 pandemic has provided an example of the ways in which the doula's role shifted from an interpersonal exchange focused on human connection within a physical space, to a more expansive role focusing on uplifting other sections of clients' lives in a more robust way.

She highlighted the importance of mutual aid in care. For example, since the inception of the pandemic, Ancient Song has given out 50–70 boxes of groceries each month, distributed 500 boxes of diapers per month, and connected community members to resources they may need within the community. "This is not just about having that episode of care or that episode of pregnancy that is happening at that particular moment, but how we are starting to create communities that are focused on sustainability and thriving," she said.

Porchia-Albert said that it is important to understand that doulas are not the answer to a systemic problem and that they are not Band-Aids to patch up a system plagued by racism and implicit bias. Rather, said Porchia-Albert, doula access is about helping birthing people have full autonomy in their human rights and their birthing experience. Doula access is about creating a cultural humility framework that lessens the power dynamics in the exam room, and understanding that episodes of care do not end at 6 weeks postpartum, and that pregnancy and postpartum are "forever."

In terms of recommendations, Porchia-Albert said it is important to understand that community is a foundation for everything, and that people inform policy, not the other way around. She said,

We should lead with community in mind, and we should also be humble about the approaches that we take when we are working with individuals, understanding that yes, data collection is important, that yes, legislative processes are important, but that these are human beings who are having a human experience.

In her view, the COVID-19 pandemic has put care providers in a place of humility about what care can mean. Within the realm of doula access, Porchia-Albert wants institutions to consider what it would mean to have doula policies that involve them in the process of development from beginning to end, to bring that community perspective to the process. She emphasized that it is important to keep pressure on districts and legislators, and remember that it serves future generations. As a final comment, she stated that centering action in community awareness, education, and legislation can help people feel more involved in the process and more open to recommendations around the ways in which health care can be decolonized in an equitable manner.

### Perinatal Quality Collaboratives

Presented by Zsakeba Henderson, March of Dimes

To start her presentation, Zsakeba Henderson noted that some of the presentations from the first day of the workshop point out that the time a patient enters the health care system is just one episode in the full spectrum of their life course. However, she said, that one episode—the time of birth—is one that profoundly affects the outcomes of mothers and their infants. Collectively, she said, the decisions that health care delivery systems make affect outcomes of care and, as others have said, there is definitely room for improvement in the quality of care that birthing people receive from these systems.

The Institute of Medicine's *Crossing the Quality Chasm* report (IOM, 2001) defines quality as "the degree to which services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." It names safety, effectiveness, timeliness, equitability, efficiency, and patient-centered as key components of providing quality care. "I think it is important to note that even 20 years ago, equity was called out as a key component of quality care, and that the ultimate goal of providing high-quality equitable care is to improve and close disparity gaps," said Henderson.

In fact, a growing body of research suggests that quality care delivered by hospitals may be a critical lever for reducing disparities and improving outcomes (Howell and Zeitlin, 2017). Data from the same study show that both within-hospital and between-hospital inequities exist for severe morbidity. Black birthing people, for example, deliver in different and lower-quality hospitals than do white birthing people, and the quality of care received during childbirth may differ by race and ethnicity even within individual hospitals.

To address some of these hospital-based quality issues, PQCs have been working in states to specifically improve the quality of care provided to mothers and their infants. PQCs are state or multistate networks of multidisciplinary teams that work to improve measurable outcomes for maternal and infant health by advancing evidence-informed clinical practices and processes using quality-improvement principles. They work with clinical teams along with various experts throughout the state, and also with partners and stakeholders, including patients and families. With these partnerships, they "spread best practices, reduce variation in care, and optimize resources to improve perinatal care and outcomes" (Task Force on PRGLAC, 2020) through three main strategies: collaborative learning, using rapid response data, and providing quality improvement science support to clinical teams. The ultimate goal, said Henderson, is to improve population-level outcomes in maternal and infant health (Lee King et al., 2020).

The collaborative learning model brings together teams to share strategies and solutions and to use evidence-based methods to reach a common objective. The use of rapid-response data, she explained, helps them make continued progress toward meeting quality-improvement objectives by providing feedback about where they are along the continuum of reaching that objective. Henderson noted that while many organizations, hospitals, and hospital systems may take on various quality-improvement initiatives and projects, PQCs have a unique role: They take on the responsibility of improving outcomes for the entire population of the region's birthing people and infants. As she explained, they understand the regional network of perinatal care, can collaborate among teams from both the hospital and in the community, and can compare the performance of hospitals that are operating within similar contexts in terms of demographics, socioeconomics, and health services availability. "Members of a regional quality-improvement initiative represent a community of change, working together toward a common objective," said Henderson.

The power of PQCs, said Henderson, comes from the fact that they play an essential role in understanding what is happening on the ground with clinical care for birthing people and newborns at both the patient and provider levels. They are able to make change at those levels and also have the ability to scale improvements statewide through the collective efforts of delivery centers and NICUs across the state. PQCs also foster hospital-level leadership and ownership of efforts, and bring together multiple partners and stakeholders to work toward a common objective to change outcomes and the culture of care. As Henderson pointed out, it is one thing to change behaviors of providers, but it is a much different and difficult thing to change culture. She also noted that it is the collective change that happens at the local level that can collectively lead to change over the state and ultimately across the country.

PQCs work without a great deal of resources. Many of them rely on volunteer effort, and engage champions within hospitals to work to improve care for their patients. Nonetheless, said Henderson, they are able to pull together teams across hospitals, including hospitals that compete against each other, to work toward improving measurable outcomes. At the same time, they are also able to involve patients and use the patient voice as a key contributor to quality-improvement efforts.

Numerous studies over the past decade have documented the ability of PQCs to improve quality of care, including by reducing early elective deliveries without a medical indication prior to 39 weeks' gestation (Gupta et al., 2017). In addition, there have been efforts around breastfeeding, neonatal care in the NICU, preventing infection, reducing maternal morbidity and mortality, reducing severe morbidity from obstetric hemorrhage, improving timely

treatment for obstetric hypertension, and most recently, around improving interventions to reduce unnecessary cesarean deliveries (Fisher et al., 2013; Kacica et al., 2017; Kaplan et al., 2018; Main et al., 2017; Rosenstein et al., 2021; Schneider et al., 2021; Ware et al., 2018).

Henderson pointed out that the number of PQCs in the country has grown considerably in the past 10 years; every state now has a PQC either currently in operation or in development (Lee King et al., 2020). She emphasized that much of this momentum has happened without funding to fully support this work. Rather, it is happening because people are passionate about improving outcomes, they want to provide better care, they want to receive the data and feedback, and they want to work together to make improvements.

At the same time, she said it was important to realize that many of these collaboratives are just getting started and have yet to reach their full potential. The lack of resources diminishes the potential to make measurable improvements in statewide maternal health and infant health outcomes. She did note that some state PQCs are being supported by CDC funding and all state PQCs can receive technical support through the National Network of PQCs, which is also funded by CDC and coordinated by the National Institute for Children's Health Quality. The mission of this network, explained Henderson, is to "support the development and enhance the ability of state PQCs to make measurable improvements in statewide maternal and infant health care and health outcomes." This network, she explained, improves collaboration across states, allowing them to share resources, to not recreate the wheel, to be able to share successes and strategies, and also to provide technical assistance to newer states to become fully functional state collaboratives.

To conclude her presentation, Henderson addressed what she called the elephant in the room: What are PQCs doing to promote and achieve equitable maternity care? "I think this is an area where there is an opportunity for more growth and more success," she said, though she did point to a few examples that have been successful at achieving equitable care and are influencing the work that other collaboratives are doing. For example, the Louisiana PQC clearly states that its main objectives are for births to be safe, equitable, and dignified. These goals are reflected in their communications campaigns and the collection of disaggregated data. Other states are trying to follow that example, and to analyze how their improvement efforts may be affecting different populations.

PQCs in Alabama, Illinois, and New York are also engaging in initiatives that specifically target inequities and improve outcomes for communities of

<sup>&</sup>lt;sup>43</sup> See https://www.nichq.org/project/national-network-perinatal-quality-collaboratives (accessed August 17, 2021).

birthing people who currently have the worst outcomes. "As these states are building the evidence base and testing strategies, more states through this network can learn from them and the various partners that are engaged in these efforts to directly address the issues around respectful care, disparities, and outcomes of maternal mortality and morbidity," said Henderson.

Turning to some of the work her organization is doing, Henderson said that in November 2020, March of Dimes entered into a public–private partnership with the Department of Health and Human Services (HHS) to improve maternal health outcomes and advance racial equity. The key activity of this partnership is a quality-improvement pilot focused on reducing the Black—white equity gap in outcomes during hospitalization at birth. On March 19, 2021, March of Dimes convened a stakeholder group of more than three dozen Black maternal health experts and advocates to guide the design of a quality-improvement pilot program. This convening resulted in a multimodal pilot, funded by United Healthcare, that incorporates supporting vaginal birth, community accountability, and respectful care. The pilot will begin at the end of 2021, and its goal is to work directly with state PQCs to strengthen their reach, sustainability, and involvement in improving equity.

In closing, Henderson said the goal of improving maternal health requires that many players come together to contribute to the success of projects that can both improve state outcomes and have the potential to collectively lead to national change. Partnerships, she said, open the door to the collaboration and sharing that is essential to what makes the PQC successful; she said she believes partnerships will be the key to move the needle on maternal health successful. "There are many opportunities for expanding this work, and I hope that by facilitating these types of partnerships and advocating to support these networks, states will help create the infrastructure and the capacity that lead to improvements in perinatal care and outcomes," said Henderson.

# IMPLEMENTATION OF STATEWIDE POLICIES AND MANDATES TO ADVANCE MATERNAL HEALTH EQUITY

The next session of the workshop featured three presentations that provided further examples of the type of work that Henderson spoke about in the previous session. The three speakers were Ann E. B. Borders (NorthShore University HealthSystem), Charlene Collier (Mississippi State Department of Health), and Nourbese Flint (Black Women for Wellness). A discussion moderated by Claire Brindis and Brownsyne Tucker Edmonds followed the three presentations.

## Birthing People and Newborns Affected by Opioids: Universal Screening for Opioid Use Disorder with a Validated Tool Strategy

Presented by Ann E. B. Borders, NorthShore University HealthSystem

In recognition of the work of the other presenters at the workshop, Ann Borders noted that part of doing the work to improve outcomes is to listen to the voices of those with lived experiences, community voices, and the voices of leaders engaging in this work around the country. With that, she turned to the focus of her work in Illinois, which is addressing substance use disorders in birthing people and their newborns, which affects maternal morbidity and mortality.

She began her presentation with a description of the Illinois PQC, which started in 2013. It includes 119 birthing hospitals that have participated in one or more initiatives covering 99 percent of the births in the state and all of the state's NICUs. Borders said that while the PQC's reach is great, what excites her most are the community stakeholders and patients who contribute to the collaborative, come to its meetings, sit on its advisory workgroups, and participate in focus groups to make sure the collaborative is centering the voices it needs to hear to do this work successfully.

Turning to the state of the perinatal substance use disorder in Illinois, Borders noted that the leading cause of pregnancy-related deaths in Illinois are mental health conditions, including substance use disorder (Illinois Department of Public Health, 2021). In fact, about 25 percent of the pregnancy-associated deaths in the state are from substance use disorder and overdose, and the rate of pregnancy-associated deaths resulting from opioid overdose increased from 1.1 to 12.0 per 100,000 live births between 2007 and 2017. "With the opioid crisis worsening," said Borders, "it is essential to identify pregnant patients with opioid use disorder and provide optimal opioid use disorder care for every patient every time to save lives." Certainly, Borders added, the COVID-19 pandemic has made things worse, cutting off birthing people from resources and leaving them isolated. She noted, too, that this is not exclusively an urban problem, as it is affecting nearly every zip code in the state. With this context in mind, the PQC voted to focus on substance use disorders.

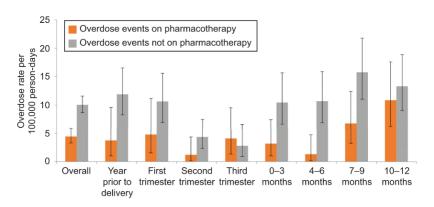
Every meeting of the collaborative is centered on patient voices, which has proven to be the most powerful way to get the attention of providers and nurses. Borders said,

It really brings the passion to this work when people are thinking of specific patient stories and that helps us get our head around that opioid use disorder is a life-threatening chronic medical condition, and that screening and linking pregnant patients with opioid use disorder to treatment services reduces

overdose deaths for moms, improves pregnancy outcomes, and increases the number of women who can parent their baby.

It is important, Borders stated, to understand that MOUD<sup>44</sup> does prevent overdose events and does save lives (see Figure 23). Data from a study in Massachusetts (Schiff et al., 2018) show that the number of overdose deaths for patients on MOUD are about half that for those who are not. They also show that the postpartum period is a particularly risky time for individuals with an OUD, making early pregnancy an even more important time for undertaking universal screening and connecting patients with care.

Illinois began its initiative to help birthing people and newborns affected by OUD in May 2018, with 107 participating hospitals. The initiative focuses on identifying pregnant individuals who have an OUD and connecting at least 70 percent of them to MOUD and recovery treatment services. The program's goals start with screening all pregnant patients with a universal, validated screener prenatally and during their labor and delivery admission. Borders stresses that this is a self-report screening tool, not urine testing; it asks patients about the experiences in their lives. For patients with an OUD



**FIGURE 23** Medication for opioid use disorder works to decrease overdoses in pregnant and postpartum patients.

SOURCES: Workshop presentation by Borders on June 8, 2021; Schiff et al., 2018.

<sup>&</sup>lt;sup>44</sup> MOUD refers to the treatments for OUD that include opioid agonist or antagonist medications (NASEM, 2019). The term medication assisted treatment (MAT) is also commonly used; however, the National Academies prefer the use of MOUD because it better aligns with the "conceptual framework of OUD as a chronic disorder for which medications are first-line treatments that are often an integral part of a person's long-term treatment plan, rather than complementary or temporary aids on the path to recovery" (NASEM, 2019, p. 18).

during pregnancy or by delivery discharge, the goal is to assess their readiness for MOUD, link them to MOUD and recovery treatment services, get them counseling and education about OUD and neonatal abstinence syndrome, and conduct a clinical care checklist, which includes naloxone counseling and hepatitis C screening, to make sure they are getting optimal care.

Borders said the program found it important to teach clinical teams key messages about what optimal OUD care is and is not. For too long, she said, the old way of thinking taught that screening was about identifying babies at risk and calling social services, which was more of a "gotcha" approach than one aimed at providing optimal care for the pregnant/postpartum patient. She explained, "We really focused on changing thinking among our providers and our clinical team to see the mom as having a life-threatening medical condition, and that we are screening them because chronic opiate use disorder is an urgent obstetric issue. We talk over and over again that it's a life-threatening chronic disease with life-saving treatment available." If providers can identify patients early in pregnancy and link them to treatment, they can reduce maternal overdose deaths, improve pregnancy outcomes, and help more patients and babies stay together after birth.

Optimal care for all pregnant and postpartum persons with OUD comes down to several elements, said Borders: Screen every patient for OUD with a validated screening tool, assess their readiness for MOUD, link them with MOUD and recovery treatment services, provide them with naloxone counseling, screen and prescribe for hepatitis C, complete a warm handoff for MOUD and recovery services, schedule a close obstetric follow-up with navigation help, provide patient education on OUD and neonatal abstinence syndrome, reduce stigma, and promote empathy across the clinical team.

One thing that she and her collaborators learned early on was that providers who conducted a screening did not always know what to do when a patient screened positive for OUD. In response, the PQC created folders called "Mothers and Newborns Affected by Opioids," which contain patient education materials and resources for clinical teams. These cover topics including prescription pain medicines and pregnancy, neonatal abstinence syndrome, contraception, and counseling that is available. Their creation was guided by patients with lived experience, who shared what they would have benefited from when they were in hospital. Borders's team also created resources for clinical team members, including an OUD/screening, brief intervention, and referral to treatment algorithm; the OUD clinical care checklist; information on naloxone prescribing; an OUD protocol; and a workflow for nurses. The materials for clinical staff emphasized addressing stigma and bias, and how to talk to patients about readiness for MOUD, and connecting with recovery treatment services.

To conclude her comments, Borders noted that since spring 2018, 92 teams have cared for more than 2,666 pregnant and postpartum women with OUD, or 71 women per month on average. They have also reported screening data for 24,430 pregnant women. When the program began, 2 percent of women who came through labor and delivery were screened with a validated tool; that number has risen to 87 percent. Routine prenatal screening for substance use disorder with a validated tool has been harder to accomplish. Though improved from a baseline of 2 percent, today, only 40-50 percent of all patients are being screened. Every team has implemented a validated screening tool that they use at labor and delivery, and 80 percent of the teams have a validated tool implemented in prenatal settings. Borders noted that there will need to be more work to improve rates of use in prenatal settings. Additionally, 93 percent of the teams involved in the initiative have a screening, brief intervention, and referral to treatment algorithm in place, have mapped community resources for individuals with OUD, have implemented an OUD clinical care checklist at the time of labor and delivery, and have implemented standardized patient education at the time of labor and delivery. She also noted that they have increased patient connections to MOUD, recovery services, and Narcan prescriptions. Borders's slides explained that Narcan/naloxone is an essential risk reduction strategy for all pregnant and postpartum patients with OUD to reduce overdose deaths. Borders noted that Narcan/naloxone counseling increased from 2 percent for all patients with OUD during pregnancy or before delivery discharge, to more than 40 percent across the initiative. The initiative had a goal of reaching 60 percent; Borders says that more work is needed to make naloxone accessible at the point of care (emergency rooms and labor and delivery). To improve rates, the initiative seeks to train all obstetric providers to counsel and prescribe naloxone for all patients with OUD or who use opioids regularly.

Lastly, Borders commented on the outcomes of the program's focus on lessening the treatment inequities between Black and white birthing people in their care settings. She noted that they decreased what had been significant disparities in rates of linkage to MOUD programs—improvements were seen for all races, but the greatest improvements in linkages were found among Black patients. The inequity in breastfeeding initiation for exposed newborns was also decreased.

Borders suggested that policies are needed to mandate that all providers screen patients in a patient-centered manner early in pregnancy and link them to care, as well as for how to improve access to MOUD for all people with OUD.

### **Building Capacity to Address Maternal Health Equity**

Presented by Charlene Collier, Mississippi State Department of Health

Mississippi has approximately 3 million people living in the state and close to 37,000 births per year, said Charlene Collier. She noted that the current infrastructure for perinatal care is lacking: There are 41 birthing hospitals, only one academic medical center that has a level-4 NICU, and 10 level-3 NICUs scattered across the state. There are 429 obstetrician/gynecologists located in 36 of 82 counties, and less than 5 percent of all births are attended by midwives. The state has no freestanding birthing centers and only one abortion provider, located in Jackson. More than 65 percent of the state's births are covered by Medicaid, and Mississippi has the highest cesarean section rate in the country, at 38.5 percent of all live births, as well as the nation's highest preterm and infant mortality rate. The greatest disparities, said Collier, fall on Black birthing people. "Any map you've seen about health indicators tends to have Mississippi on the bottom of it, and to be clear, Mississippi serves as a clear example of the impact of racism on health in a population," she said.

Echoing the presentations of her colleagues, Collier reminded the audience that chattel slavery and Jim Crow have been particularly dangerous for and harmful to Black women. She provided the example of Fanny Lou Hamer, who suffered an involuntary hysterectomy—a Mississippi appendectomy, as it was called. At the time, Hamer estimated that close to 60 percent of the women in her county of South Sunflower had also endured involuntary hysterectomies, and Collier noted that South Sunflower today sees some of the worst inequities in maternal morbidities. Collier noted that it was only in 2020 that the state removed the Confederate battle flag from the state flag, and stated that this demonstrates a legacy of white supremacy that still persists in the state and its politics.

As a result of these factors, the disparity in maternal mortality in Mississippi is striking, with white women experiencing 18.9 deaths per 100,000 live births compared to 51.9 deaths per 100,000 live births for Black women. Some 14 percent of pregnancy-related deaths occur during pregnancy, with 37 percent occurring with 6 weeks postpartum when most mothers and birthing people no longer have Medicaid coverage, and 49 percent occurring after 6 weeks postpartum. More than 50 percent of those deaths occurred while the individuals were inpatients. Moreover, some 70–80 percent of deaths from cardiovascular conditions and severe hypertension were among Black mothers. In Mississippi, complications related to hypertension and heart disease are the leading causes of pregnancy-related mortality, yet most are preventable.

The disparities do not end with mortality, said Collier, with American Indians of the Choctaw Nation and Native Alaskans experiencing the highest rate of severe maternal morbidity in terms of percentages, followed by Black birthing people and Asian birthing people. Black women account for more than 57 percent of severe maternal morbidity events.

Although the Mississippi PQC was formed in November 2014, it took two failed attempts before the Mississippi legislature created the Mississippi MMRC in 2017 to provide the data needed to inform the PQC. CDC provided funding in 2018, at which point the PQC joined the National Network of PQCs. MMRC issued its first report in 2019, which Collier said seemed like a heroic event that finally provided access to comprehensive data on maternal mortality.

In many ways, though, Mississippi continued missing the mark on equity in this report, said Collier. Despite identifying major gaps in evidence-based obstetric care and creating needed recommendations, MMRC focused largely on the medical record as a data source, which Collier said erases the story of the birthing person. As a result, the committee overemphasized clinical conditions, both in the data and in its recommendations, and had a lack of patient input and family voice. That first report in 2019 avoided discussing racism and politics as sources of disparities, she noted, and omitted structural recommendations in these areas that are needed to drive change.

In an effort to continuously improve the Maternal Mortality Review process, Collier and others working on the committee raised the question of whether MMRC was equipped to address inequities and Black maternal mortality. They asked whether the committee was using data sources that had been evaluated for racism and bias themselves, or that adequately included the perspective of pregnant and birthing people and their families. They also wondered about the makeup of the committee itself: Did it have representation and inclusivity in its committee members; did its members have any knowledge about health equity, the SDOH, and racism as underlying causes of Black maternal health inequities; were they aware of Black community strengths, solutions and scholarship? Lastly, they asked whether MMRC had any influence or authority to create policy and order systems-level change.

With the production of that 2019 report, the Mississippi PQC and the Mississippi Department of Health formed a separate committee that specifically targeted equity to address racial and socioeconomic inequities. The equity committee started by addressing the makeup of MMRC itself. They removed limits on numbers and term limits to improve access to participating. Additionally, typically, the state uses a process of requesting nominations for membership on its committees from professional organizations, but that produced an overwhelming number of white members being recommended because they were overrepresented in those professional organizations. To address that, the committee now allows for multiple members within roles—social work or nursing, for example—to ensure equity and racial and geographic concordance across positions. The review committee is also adding patient advocates, Black

community mental health workers, and domestic violence specialists to the committee in 2021.

MMRC now has an equity subcommittee that is developing and applying a health equity framework to all of the larger review committee's work. The equity subcommittee, said Collier, also serves to provide space and time to acknowledge, discuss, and develop solutions to structural and interpersonal racism, discrimination, and the SDOH that particularly affect Black communities and birthing people. It also is developing enhanced skills in interpreting and applying SDOH data. Equity subcommittee members were able to participate in an equity pilot program with CDC that used a social-special dashboard of metrics that capture key community factors, such as general health, reproductive health, behavioral health, transportation access, and socioeconomic context (Kramer et al., 2019).

Collier gave credit to CDC and its MMRIA team for promoting committee education and allowing the committee members to learn about how it can infuse equity into all aspects of the review committee's work. In June 2021, the committee launched birth equity trainings with NBEC for all review committee members.

Another aspect of the process that the equity committee sought to improve was to humanize the birthing person. The mortality review process now assigns each case a pseudonym rather than a case number in an effort to humanize each birthing person who died. Information on race, ethnicity, socioeconomic status, employment status, marital status, insurance status, and education level are listed at the end of the event presentation rather than at the beginning, so that biased personal judgments do not enter into the review process. Collier said that a question about whether discrimination contributed to a death has also been added to the review process, and its scope has broadened to capture cases that might be considered to be pregnancy related, such as suicide, drug overdose, and most recently, homicide. She added that they had noticed a particularly large disparity in pregnancy-related homicides, with Black birthing people being the most impacted.

Collier said she was particularly proud of the addition of informant interviews to the process. A licensed clinical social worker trained in trauma and bereavement counseling uses the informant interviews to extract information or data from the surviving family members and also provides them with resources and connections to services. "This has been truly transformational in uncovering details that were omitted from the medical record, such as out-of-hospital events, perceptions of care, and experiences of discrimination, and providing a holistic view of that person's life," said Collier.

With these changes, MMRC made its first recommendation, which was to extend Medicaid to 12 months postpartum. Unfortunately, Mississippi lawmakers removed this provision in the 2021 legislative sessions, citing cost.

ADVANCING MATERNAL HEALTH EQUITY

The committee is now engaging lawmakers for the 2022 session and also promoting a policy change to support doula payment and midwifery care. She is proud to be using CDC funds to support Mississippi organizations led by Black women that are addressing gaps in care and showing that the solutions are present within the community. For example, the MomMe program, led by two Black mothers from Mississippi, is now able to provide mental health services and has done so for more than 200 mothers in the state.

## California's Dignity in Pregnancy and Childbirth Act and Maternal Health Policy

Presented by Nourbese Flint, Black Women for Wellness

Black Women for Wellness, explained Nourbese Flint, is a reproductive justice organization formed in south Los Angeles in 1997. One of its first programs was looking at maternal and infant health, given the high number of maternal and infant deaths in the Black community. The Black Women for Wellness Action Project, a 501(c)(4) organization, 45 was formed in 2017 to address political and policy issues and was the first Black reproductive justice 501(c)(4) in the nation, and it is still the only one in California. In her presentation, Flint described the development of policies to address racial inequities in maternal health care in California.

Flint noted that over the past 30 years, California has seen a reduction in the overall death rate for birthing people. However, she explains that "buried" in these positive trends are persistent inequities; there has been no reduction in the inequities Black women and birthing people are experiencing. Between 2011 and 2013, for example, the death rate for Black women was 26.4 per 100,000 live births, almost 3.8 times higher than that for white women, and in Los Angeles County it was 4.5 times higher for Black women compared to white women. In fact, the death rate for Black maternal mortality in Los Angeles increased from 58.6 per 100,000 live births in 2013 to 85.8 per 100,000 live births in 2018, compared to 17.9 deaths per 100,000 live births for all women in Los Angeles County in 2018. Collier also cited statistics for infant mortality, which overall was 4.2 deaths per 1,000 live births in the state. Highlighting stark inequities, Indigenous/Native American infants in California die at a rate of 11.7 per 1,000 live births, whereas Black infants die at a rate of 8.7 per 1,000 live births.

California has conducted qualitative research showing that pregnant and postpartum people who are Black, Indigenous/Native American, and/or

<sup>&</sup>lt;sup>45</sup> A 501(c)(4) organization must not operate for profit and must be operated exclusively to promote social welfare.

people of color also face mistreatment at hospitals at higher rates than their white counterparts. Higher numbers of Black, Asian, and Pacific Islander pregnant and postpartum people report unfair treatment, harsh language, and rough handling during labor and delivery hospital stays as compared to their white counterparts (Sakala et al., 2018). This research also found that higher numbers of pregnant and postpartum people who speak an Asian Language or Spanish at home reported unfair treatment during their labor and delivery hospital stay, as compared to pregnant and postpartum people who speak primarily English at home. Collier noted, too, that California has not published updated statewide data on maternal mortality since 2015 and does not have a codified MMRC, PQC, or any requirement codified in legislation to address racial inequities in maternal and infant outcomes. Moreover, California has an obstetrics/gynecology workforce shortage, particularly in parts of the state with large populations.

To address some of these issues, Flint said, she and her colleagues have worked on several pieces of legislation, and she highlighted two of their projects. One bill that passed last year, California SB 1237, 46 removed physician supervision from certified midwives; California had been one of only four states that had that requirement. In particular, she focused on SB 464, the California Dignity in Pregnancy and Childbirth Act. 47 This bill, which became law on January 1, 2020, is an attempt to start addressing discrimination and racism within the maternal health system. Its primary focus was to mandate biannual evidence-based implicit bias training for perinatal inpatient providers, with the larger aim of shifting the paradigm for racial justice. She explained, though, that there was another motive behind pushing this policy. "What we wanted to do was bury racial justice training within an implicit bias framework to push our physicians and all our perinatal staff into thinking about racial justice in a different paradigm," she said.

Though Flint's presentation focused on the implicit bias training at the center of the legislation, SB 464 also has several other pieces that contributed to this aim of achieving racial justice. First, it improves death certificate reporting to produce a more accurate maternal death count for California, and also requires that data be disaggregated by race and geographical area to allow for equity analysis. The bill also mandates that hospitals and perinatal service providers give education to patients about reporting experiences of discrimination in health care services.

<sup>&</sup>lt;sup>46</sup> For more information about California SB 1237, the Justice and Equity in Maternity Care Act, see https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=201920200SB1237 (accessed August 18, 2021).

<sup>&</sup>lt;sup>47</sup> For more information about SB 464, see https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill\_id=201920200SB464 (accessed August 18, 2021).

Turning back to the implicit bias training, Flint noted that conversations with colleagues around the country revealed that there was not much precedent for policy addressing evidence-based implicit bias training; with that in mind, her team views SB 464 as a test of how this could work in practice.

Flint said she envisioned that hospitals and birthing centers would establish in-house programs, which is why SB 464 is not prescriptive about who should do the training. Instead, the law is prescriptive of the curriculum, which includes 10 components that similar programs have found important<sup>48</sup>:

- Identify previous or current unconscious biases and misinformation (by taking an implicit bias test).
- Identify personal, interpersonal, institutional, structural, and cultural barriers to inclusion.
- Introduce corrective measures to decrease implicit bias at the interpersonal and institutional levels, including ongoing policies and practices for that purpose.
- Provide education on the effects of historic and contemporary exclusion and oppression of minority communities.
- Provide education on cultural identity across racial or ethnic groups.
- Improve effective communication across identities, including race, ethnicity, religion, and gender.
- Address power dynamics and organizational decision making.
- Discuss health inequities and the impacts of implicit bias on maternal and infant health outcomes.
- Share perspectives of diverse, local constituency groups and experts on particular racial, identity, cultural, and provider-community relations issues in the community.
- Educate on reproductive justice.

The first two items serve as a means of having people take an implicit bias test. Flint explained that an important part of the training is creating space to have difficult conversations among staff members who experience implicit bias in dealings with their colleagues. "We wanted to make sure that there were some corrective measures to decrease implicit bias at the interpersonal, institutional levels," she said.

Unfortunately, the COVID-19 pandemic struck just as programs would have gotten started, which turned the focus of the maternal health care system to addressing the pandemic rather than addressing racial justice. As a result,

<sup>&</sup>lt;sup>48</sup> See https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill\_id=201920200SB464 (accessed August 17, 2021).

not many places have implemented the training in the way she had hoped. Another barrier turned out to be that physicians, because of the way they are classified as workers in California, are for the most part not accountable for taking this training, nor any other training mandated in the state, including sexual harassment training. In addition, SB 464's passage gave birth to a new industry of people who said they could offer implicit bias training in an online format, which was not something she envisioned. "Our thinking in the design was that we wanted people to be in space with each other to be able to have these discussions, not clicking through an online piece," said Flint. She and her colleagues are now exploring ways to provide funding through the state budget process to incentivize smaller hospitals to provide the rigorous and robust training that the law's sponsors envisioned would occur.

Going forward, Flint said that SB 464 is just the beginning of addressing maternal mortality and morbidity in California. At the time of the workshop, SB 65, the California Momnibus Bill, was working its way through the state legislature. This bill would establish and codify the California Pregnancy-Associated Review Committee within the California Department of Public Health, an MMRC, to "continuously engage in the comprehensive, regular, and uniform review and reporting of maternal deaths throughout the state."49 It would require diversity in membership on the committee, a goal that had also been a goal of Collier's work in Mississippi. It would also update the Fetal and Infant Mortality Review process to "investigate, track, and review those deaths." <sup>50</sup> In addition, the bill would establish a program to increase student attendance and placement of certified nurse midwives and license midwives of color, extend postpartum Medicaid coverage through Medi-Cal from 60 days to 1 year, and require Medi-Cal coverage for doulas. Finally, the bill would update the CalWork Pregnancy supplement, which has not changed since 1983, and create a guaranteed income pilot program that would provide CalWork participants with monthly cash aid from 6 months of pregnancy to when their child is 2 years old.

#### Discussion

Brindis opened the discussion by asking the speakers from the day's first two panels to address how they might scale some of the interventions they discussed in their presentations. Borders replied that Illinois is working on

<sup>&</sup>lt;sup>49</sup> See https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=202120220SB65 (August 17, 2021).

<sup>&</sup>lt;sup>50</sup> See https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=202120220SB65 (August 17, 2021).

carrying that momentum forward both by expanding within their state, and by sharing their strategies and successes with other states. One such effort is that it has started a statewide birth equity initiative and has 76 hospitals enrolled, in part because of the widespread media attention the program has received in the state. This initiative will work on four key drivers:

- establishing universal screening for the SDOH and getting every hospital to review its maternal health quality data by race, ethnicity, and insurance status; identifying disparities; and finding local opportunities for improvement;
- engaging patients and communities in the quality-improvement work that promotes patient-centered and respectful care practices;
- instituting postpartum safety programs that include helping new mothers go home with an understanding of early maternal warning signs and setting up a 2-week postpartum appointment prior to discharge; and
- creating implicit bias training programs, such as those described by Flint.

Collier said that adding accountability at the payer level can be a driver of broader adoption of effective programs. In Mississippi, participating in the PQC was initially voluntary. Blue Cross & Blue Shield stepped up and made participation in her agency's quality collaborative required for all in-network hospitals, which was enough to get hospital administrators involved in promoting action. Henderson said she would like to see accountability extended to transparency with data and collecting data stratified by race, ethnicity, and other demographic factors so that birthing people can make informed choices as to where they want to go to give birth. She also stressed the importance of including the patient voice in the process of both developing programs and disseminating them.

When it comes to California, said Flint, having a statewide program is already "scaled up," given the size of the state. The bigger challenge in California, as she sees it, is redefining what success looks like in such a large state, where there can be pockets of inequities that do not get the attention they need if the state average on a metric is fine. The idea, then, is to define success in terms of how the birthing experience can be improved for marginalized communities, or in poorly performing hospitals, so that everyone in the state is having a joyous birthing experience. She added that one barrier to adoption of successful programs in California, in her opinion, is from the so-called experts in the state who are entrenched in the old ways of doing things. "We need to be thinking about how do we diversify who we think are experts in

the conversation.... Diversifying the people who can add their expertise and real-life experience to the work would be helpful," said Flint.

Borders added that diversifying the health care workforce and the voices who are helping to make policy and do the work is also needed to help drive the policy discussions around issues such as how to get more patient navigators, doulas, breastfeeding peer counselors, midwives, and providers and nurses of color into the pipeline. She noted that many states are looking at policies that would address those and other issues around maternal and infant health and are trying to determine what legislation and regulations would be helpful, particularly in terms of diversifying the workforce given the data showing how important that is for positive patient experiences. The postpartum period needs more attention, too, said Borders, given how little attention it has received in the United States, particularly compared to other wealthy nations.

Tucker Edmonds then asked the panel members to comment on their efforts to promote collaboration among the key players in the spaces in which they are working, and what barriers or facilitators they have encountered. One barrier Henderson identified arises from the way in which this country educates its health care teams. "We are not exposed to other members of the team until we are out of our training and in the workforce," she said. As an example, she noted that there are only a few obstetric and gynecology programs that offer exposure to midwifery training and vice versa. A significant facilitator of collaboration, then, would be to provide additional exposure during training to different members of the maternity care team. Dr. Collier seconded that idea, noting that tensions between different parts of the team may be deepened by a scarcity mindset over who will be paid for delivering what services, and poor collaboration among competing medical associations.

Borders said that an important barrier relates to the need to extend the obstetric workforce to include more lay health workers, doulas, birth counselors, patient navigators, and midwives and how to pay for their services. She noted that her academic medical center has taken the out-of-the-box step of hiring lay breastfeeding counselors to be part of the obstetric team and is now trying to figure out how to reimburse them, but more importantly, how to make them feel comfortable and ensure they are treated as a true part of the team. Dr. Henderson echoed the importance of incorporating other types of birth workers into the team. However, referring back to Porchia-Albert's presentation, she reminded the audience that some of the policies that attempt to formalize reimbursement for services, such as those for doulas, can end up being counterproductive and actually serve to restrict access. She referred to a similar case that had occurred in Georgia, in which legislation intended to reimburse Internationally Board-Certified Lactation Consultants for breastfeeding support would have restricted other types of providers from also being

able to support a birthing person, and ultimately hurt access. She suggested that those policies should be written carefully.

Flint, too, echoed the points raised by her colleagues, and additionally emphasized how political dynamics can be a significant barrier to expanding the health care team. In California, the most vocal opposition to health care team expansion and the expansion of scopes of practice is the California Medical Association, and sometimes ACOG. She mentioned that it is important that such professional associations monitor for racism within their policies.

Brindis called on Saraswathi Vedam to share her thoughts about incorporating implicit bias and antiracism work systemically in care settings. Vedam, noting the importance of antiracism training, also emphasized that antiracism training is a lifelong process, said that implicit bias and interpersonal racism are not going to be addressed in a single, 1-hour webinar or in-person training. She believes there should be a standard for who can provide these trainings and what these trainings include. At the Birth Place Lab, she and her colleagues are creating a quality assurance system for scoring different domains that contribute to quality care. These ensure that systems are not just accountable for the outcomes of medical procedures but for the quality of interactions, too. Borders agreed and noted that, as part of the Birth Equity Initiative, the Illinois PQC is going to help hospital teams provide patients with a QR code, an image they can scan with their phones, before delivery discharge that will send them a patient experience survey. This survey will assess whether the patient was listened to and received respectful care during labor and delivery. The survey results will go directly to hospitals to share with their nurses and providers as a form of active feedback for quality improvement. As a final comment, she said that it is imperative to go beyond having hospitals talk about these types of programs and start putting these strategies into action; they must also create accountability and feedback mechanisms to measure whether culture change is occurring.

## PROMISING STRATEGIES USING A REPRODUCTIVE WELL-BEING APPROACH TO ADVANCE MATERNAL HEALTH

The third session of the day addressed efforts at the state and local levels to address maternal health through a framework of reproductive justice. The four speakers were Aza Nedhari (Mamatoto Village), Ebony Marcelle (Community of Hope Family Health and Birth Center), Camie Jae Goldhammer (Native American Breastfeeding Coalition of Washington and National Association of Professional and Peer Lactation Supporters of Color), and Grace Lubwama (YWCA Kalamazoo).

### Mamatoto Village

Presented by Aza Nedhari, Mamatoto Village

Mamatoto Village, explained Aza Nedhari, is a Black woman–led organization in Washington, DC, and Prince George's County, Maryland, and is devoted to serving Black women and families by creating career pathways in maternal health and providing accessible perinatal support services. These services are designed to equip birthing people with the necessary tools to make the most informed decisions in their maternity care, parenting, and lives. Toward that end, Mamatoto offers comprehensive perinatal support in terms of both clinical and nonclinical services and home visiting that bridges the gap for communities exiting on the margins. <sup>51</sup> Its work is relationship based and centered on reproductive justice, which to Nedhari means supporting birthing people in their right to have children, to not have children, and to parent those children in communities of safety and dignity. Ujima, one of the seven principles of Kwanzaa, undergirds their work; it is the principle of collective work and responsibility.

Nedhari explained that her organization embodies its espoused values in the mnemonic I.CARE.SIS—inclusion, collaboration, advocacy, respectful care, equity, support, integrity and accountability, and service—that builds on a framework reflected in Mikki Kendall's *Hood Feminism* (Kendall, 2020). It promotes collective care to dismantle the ineffective systems of support for Black mothers and families. Nedhari said,

This is a framework that helps us acknowledge that the methods and compensatory behaviors that Black birthing people use for survival in a system of racism and white supremacy deserve understanding, curiosity, and grace, not judgment or repackaged respectability narratives to appease those who say, "I support Black women" except only in certain cases or only for certain Black women.

She noted that her organization focuses not only on Black women, but also on all Black birthing people regardless of gender identity.

She explained that Black women in the District of Columbia are four times more likely than the national average to die during or after childbirth (Hawkins et al., 2019); a Black infant born in the most disinvested ward in the city is 10 times more likely to die during or within the first year of birth when compared to infants living in the wealthiest ward (DC Department of Health, 2016). In addition, families living in the most underresourced areas of

<sup>&</sup>lt;sup>51</sup> See https://www.mamatotovillage.org/about.html (accessed August 17, 2021).

the city, compared to the wealthiest, experience higher levels of food insecurity, limited access to dignified health care, and disparate rates of unemployment.

Mamatoto's work, said Nedhari, encompasses two distinct areas: service and social investment. Its Mothers' Rising program is its home-grown model of home visitation. It is based on evidence-based tools for delivering comprehensive perinatal support in a team-based approach for the first 3 months postpartum. Medicaid-managed care contracts in the city provide the majority of this program's funding; all home-visiting services, including labor support, lactation, mental health, and in-home postpartum care, are covered benefits. She noted that this arrangement provides a stable source of revenue that has allowed Mamatoto to innovate in a way that might not have been possible with more restricted access to funds. She added that contracts are feefor-service and capitated, though Mamatoto is moving to engaging in more value-based contracts with payers.

In 2020, Mamatoto served more than 350 Black mothers, babies, and families despite having to move into a completely virtual space because of the COVID-19 pandemic. Nonetheless, the program was able to maintain the zero maternal mortality rate that it has maintained since it started. Other statistics Nedhari cited from 2020 include 91 percent of the birthing people they served achieved a full-term delivery, 90 percent initiated breastfeeding, and 80 percent of its clients gave birth to a baby of healthy birthweight. It also delivered 5,000 diapers, more than 50 emergency food bags, and engaged in more than 3,700 telehealth visits while maintaining an 84 percent participation rate for its clients.

The other major piece of Mamatoto's work is to cultivate wealth and build social capital through a perinatal workforce training program. Nedhari explained that this is rigorous training that includes more than 200 hours of instruction. In Nedhari's words, "we believe that wealth is already in the community, and all we are doing is tapping that wealth and being a convener for people to have a space for self-determination." The training program uses a community health worker framework, which is applied both to focus intently and in-depth on the physiologic understanding of the perinatal period, and also to emphasize the history of maternal and child health practices. It centers on reproductive, social, and birth justice, as well as the psychosocial factors, policies, and systemic racism that affect reproduction, pregnancy, and parenting in the program's priority communities.

Discussing the future of the organization, Nedhari said it is a future in which Mamatoto is birthing a movement of justice and collective care. In 2022, Mamatoto is opening a new space in the heart of the city's seventh ward, which will anchor it in that community for the long term and allow it to expand its services and programs to include a full-spectrum clinic, midwifery

and perinatal community health worker training, a milk depot and lactation clinic, mental health services, a family essentials pantry, and additional client meeting rooms.

She noted that the policies and advocacy initiatives her organization is fostering in its community require a reckoning with a legacy of medical racism and its symbiosis with manifestations of economic and gender justice. "We are shifting the dynamics of community engagement toward community ownership," said Nedhari. In that respect, she said,

Mamatoto has always been a conduit of resources that amplifies the voices of Black women and their families to be witnessed, funded, and elevated as subject-matter experts of the lived experience at the intersection of multiple oppression identities and the change agents who identify and evaluate the implementation of justice and are community solutions.

In addition, Mamatoto is scaling social change processes. "We have acknowledged, lived, and witnessed the tides of oppressive systems that have evolved to maintain the status quo of adverse health outcomes across the personal and generational lifespan of Black families," said Nedhari. "As a method of accelerating this change, Mamatoto commits to documenting, sharing, and replicating community-based social change initiatives among a national network of regional partners to leverage present day interest and action toward health justice." For her, she added, this takes the form of a village keeper council of community voices, justice-based collective impact partnerships that move beyond the "ancillary and predatory practices of memoranda of understandings to create networks of coalitions that are fueled with the knowledge of village keepers, a perinatal health corps and dynamic, regional, and national partnerships."

Nedhari said that when people ask her how Mamatoto is different from other social services organizations, she said that the greatest differentiator of its model is that its staff totally reflects the communities and clients that it serves, as does its thought partners, the way it innovates, its strength-based solutions, and its strategic actions. "This social and cultural proximity has been the driving force in our success," she said.

Another differentiator is the three-generational framework through which Mamatoto operates. "As a trained marriage and family therapist, I believe that the individual is best understood through the family and environments that nurture them," she said. This three-generation approach, Nedhari explained, is an upstream solution that recognizes the significance of the intergenerational transmission of health, well-being, and social status; it emphasizes the need to look back to create stability for the birthing person's support system to facilitate a move for their entire family toward self-determination.

Lastly, she underscored the importance of the conscious effort that the organization takes to apply their tenets of justice to internal structures, policies, and practices, and not just to the services that they provide to clients.

## Reproductive Justice Influence in Community Health: Midwifery Model in a Federally Qualified Health Center Birth Center

Presented by Ebony Marcelle, Community of Hope Family Health and Birth Center

To start her presentation, Ebony Marcelle echoed the point made by many of her colleagues at the workshop, that it is impossible to have a conversation about health disparities without talking about racism and how it affects health care, especially as that care is being delivered to Black birthing individuals. In her presentation, Marcelle focused on the Community of Hope program, which serves low-income and Black families in the District of Columbia, and described its services and philosophy. She talked about how racism manifests within community health maternity care settings, specifically.

Marcelle noted that the manifestation of racism from the perspective of patients is different from the perspective of providers. Patients experiencing racism in a maternal health care setting may experience microaggressions and harms, and develop feelings of avoidance or mistrust. They may have access to only the lowest cost options available, more restrictive care options, and care options that are incompatible to people working full time or relying on long commutes on public transportation.

Marcelle said that there are still providers who believe the racist myths about biological differences or exhibit biases and stereotyping among providers, there is an overall lack of cultural awareness and a perpetuation of white supremacy systems and blame narratives, she noted.

Marcelle turned her attention to how these dynamics of racism in care spaces manifest for birthing people in the District of Columbia, specifically, as this is where her organization's services are based (see Figure 24). In 2018, the DC Primary Care Association (DCPCA) conducted interviews with women in the regions of the city that have some of the worst birth outcomes. DCPCA found that these birthing people, most of whom were Black, reported not being listened to by their providers and not having great experiences overall with their providers (Russell et al., 2018). Nevertheless, Marcelle noted that providers sometimes think "we are all doing the right thing, not realizing that we are absolutely causing harm to Black families." Marcelle pointed out that the District of Columbia still does not have a hospital with obstetric services that is east of the Anacostia River, which means that there is no convenient access to services for high-risk birthing people living in that area, which is a

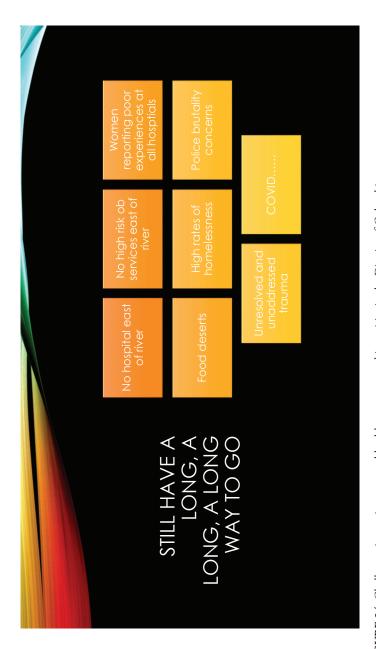


FIGURE 24 Challenges impacting maternal health outcomes and inequities in the District of Columbia. SOURCE: Workshop presentation by Marcelle on June 8, 2021

primarily Black and low-income area. Birthing people in the city still report poor experiences at all of the city's hospitals, as well as compounding issues with environmental hazards, violence, homelessness, and food deserts, all of which create underresolved and unaddressed trauma. She notes that Black birthing families are especially impacted by these issues.

Community of Hope works to address these factors. Though it began as an organization dealing with housing insecurity, it has since grown into a patient-centered medical home over the past 15 years. What makes Community of Hope unusual is that it is one of only five FQHCs in the nation that includes a birth center, and is the only freestanding birth center in the District of Columbia. Marcelle noted that she largely takes care of Black birthing families, 90 percent of whom live at or are below 200 percent of the federal poverty level. The majority of their clients live in Wards 5, 7, and 8. the geographic areas of the city with the worst birthing outcomes.

Community of Hope's program has 10 midwives on staff, 4 family practitioners, and 1 family nurse practitioner providing prenatal care. All births are handled by the midwives, though Marcelle said the birth center is not used as much as it should be. Care coordination services are provided by a perinatal care coordinator, a group care coordinator, and a reproductive health coordinator. The program also provides home visitation, lactation support, parenting groups, doulas, and integrated behavioral health care. Prior to the COVID-19 pandemic, Community of Hope also ran postpartum groups, which will resume at some point in the future.

Marcelle then described the reproductive justice framework that her organization uses in maternity care, and discussed lessons learned. She said that implementing such a framework should start with the acknowledgment and awareness that the current situation for most families is not good and that there is much room for improvement. "I think that has been one big pill to swallow for different individual systems and organizations, but it is true," she said. Marcelle also contended that there are many punitive elements in the current maternal health system which prevent the creation of a space in which birthing people feel they are safe. She said that a system that operates with a reproductive justice framework requires that care is patient- and family-centered and reflects the wants and needs of families; shared decision making is the norm; the system supports cultural congruency with providers; and it removes those policies that are punitive and create barriers to care.

She also highlighted the importance of patient-centered care coordination. She expressed that she believes many providers want to avoid "holding people's hands," and challenges this notion—she suggested that providers should want to hold their patients' hands, lift their patients up, and provide support. Marcelle also emphasized the need to develop programming that nurtures collaboration with the community being served. Care continuity must

be prioritized as much as possible, said Marcelle, as should relationship-based care, which she said has been shown to lead to better outcomes.

If she were to dream of a better future, Marcelle said, she says there would be no disparities or inequities, that access and quality would not be a question regardless of where one lives, that there would be more out-of-hospital birthing options, and that midwifery would be mainstreamed in all settings and all pathways. She would also dream of a world in which midwifery were aligned with physician colleagues to enable collaboration, co-management, or transfer for patients who are experiencing complications during pregnancy. There would be more Black providers in all specialties and related services, where cultural congruency would be prioritized, and doulas, lactation assistance, and care coordination would be standard components of care and covered by insurance. For out-of-hospital community birthers, she would like to have safe places and more collaboration for transfer. Marcelle said she would hope the future provides more infertility assistance for low-income families, and for ongoing, consistent, and regular bias training to be built into clinical education. Finally and overarchingly, she said, she wants to have a world in which Black birthing families have beautiful and transformative births where they feel "seen, heard, cared for, and loved."

# The Role Community-Designed Programs Play in Reducing Infant and Maternal Mortality for Indigenous Communities

Presented by Camie Jae Goldhammer, Native American Breastfeeding Coalition of Washington and National Association of Professional and Peer Lactation Supporters of Color

To begin her presentation, Camie Jae Goldhammer shared that she is Dakota, her tribe is Sisseton-Wahpeton, and that she today lives in the occupied territory of the Duwamish people, which is also known as Seattle. She described the Hummingbird Indigenous Doulas program that she started. This community-designed, culturally responsive, full-spectrum Indigenous doula program arose out of the need to address the disproportionately high maternal mortality rates of Indigenous people in King County, Washington, and throughout the Puget Sound area. She noted that Native American, Alaska Native, and American Indian pregnant people have the highest maternal mortality rate in Washington State, where they die at almost 11 times the rate of white parents and about four times the rate of Black birthing people. She also pointed out that she feels that as an Indigenous doula, she and the other Indigenous doulas are the protectors of their people. "It is our traditional role and our birthright to serve pregnant people in any way that they need," said Goldhammer.

As a full-spectrum doula program service, her organization has supported pregnant people regardless of the pregnancy outcome and in a variety of ways. One doula, for example, has supported a single mother by choice through her fertility journey and has been a partner through her inseminations. Another doula is supporting a family through an ectopic pregnancy, and they offer abortion support. Goldhammer said that all of her organization's clients have to identify as Native American, Alaska Native, First Nations, Pacific Islander, or Native Hawaiian. There is no income requirement because, as she puts it, income is not protective against dying, being abused, having a traumatic birth, or interfacing with racism, discrimination, and oppression in the health care system.

In its first year of service, the program served 53 families, which was more than double the 25 families that the program had been contracted to serve, according to its initial grant. At the time of the workshop, they had expanded to serving 70 families. Nearly 90 percent of babies they served were delivered vaginally, as compared to the typical 73 percent in their area. Ninety percent of the vaginal deliveries were unmedicated, as compared to 32 percent of births in their area. Thirty percent were born out of hospital, and only 4 percent of all of their clients were born prematurely; in King County, the rate of premature births for Native families, regardless of birth setting, is 12 percent. Every mother initiated breastfeeding, compared to 70 percent for Native families in general, and for those families who lost a pregnancy, the program provided ongoing support. Regarding the 30 percent of families who chose to deliver outside of hospital, Goldhammer said that was not an intention of the program but rather was a result of the families feeling empowered, being heard, being told they have choices, and being connected to resources. Some families during their intake interview will say they want a home birth but believe they are high-risk individuals and cannot. However, when offered resources to enable home birth, they may choose to do so.

Goldhammer explained that she sees the program as being traditional in that it treats pregnancy as her ancestors did. "We see doula support, lactation support, as a traditional practice, as a cultural practice that we are working hard to reclaim for our community," she said. She noted, too, that the program is strongly connected to larger Indigenous birth communities throughout Canada and the United States.

Families come to the program for many reasons. In some cases, a family may want a Native doula, and they want someone who knows them, who looks like them, and who has some connection to their culture. Some of the program's clients are disconnected from their culture or the Indigenous community and come to the program because they see having a baby as a time to reclaim those traditional practices and pass something down to their children. "They come to us to get reconnected in a good way," said Goldhammer. The

program, for example, makes its clients traditional meals that align from their respective cultures, researches any relevant practices with which they may not already be familiar, and conducts traditional postpartum ceremonies, such as singing or preparing a cedar bath for the birthing person after delivering their baby.

Goldhammer then transitioned to describe another program that she created, called the Indigenous Breastfeeding Counselor educational program. She saw the need for such an organization when she herself went through the process to become an Internationally Board-Certified Lactation Consultant. During 2 years of training, she felt that she learned from white mentors how to serve white birthing people well, which did not align with her career goals, as she planned to serve the Indigenous community. To address the lack of options for Indigenous birth workers seeking to become breastfeeding care counselors, she created a 5-day, 45-hour course. Goldhammer called it a foundational breastfeeding educational course that is clinically intensive, but also completely Indigenous. "We really see breastfeeding or lactation as a traditional and cultural practice," she said. "We believe that it is the community that is to be the stewards of this education and support."

The program has two educators, Goldhammer and Kimberly Moore-Salas, a Navajo lactation consultant based out of Arizona. Every person that takes the course has to identify as Native. At the time of the workshop, the program had trained more than 220 Indigenous breastfeeding counselors in 10 courses, with 16 courses scheduled for 2022.

## Promising Strategies Using a Reproductive Well-Being Approach to Advance Maternal Health

Presented by Grace Lubwama, YWCA Kalamazoo

When Grace Lubwama came to Kalamazoo from Los Angeles as a public health expert, she wanted to find out if it was a community that she could enjoy with her friends and family and where she could raise her two sons. With her public health training, she knew that infant mortality is an indicator of how well a community is taking care of its most vulnerable citizens and speaks to deeper social issues that are occurring in a community. As Dr. Lubwama explored the health indicators in the Kalamazoo community, she found that there was such a high inequity in outcomes between Black babies and white babies in Kalamazoo, and based on the mission of the YWCA, felt that it was something the YWCA could affect in an intentional way while mobilizing the community to act. "We knew that if we addressed the infant mortality disparities, we would definitely be going to be taking care of the mothers in our community and the children in our community," said Lubwama. She also

noted that the YWCA's mission is about Eliminating Racism and Empowering Women, illustrating the organization's prioritization of a higher calling of intentionality around the intersectionality of race and gender equity.

Lubwama described Kalamazoo as a progressive community. As an example, she shared that it offers what it calls the "Kalamazoo Promise," an initiative that provides the opportunity for every child that graduates from the Kalamazoo Public School system to attend a college anywhere in Michigan without any cost. "But one of the things that we did not think about when this was launched 10 years ago is using education as an intervention to reduce inequity," both social and economic, she said.

Lubwama said that it was in the same progressive spirit that the YWCA mobilized the city's residents, community partners, local government agencies, and funders to create an initiative with the vision that every baby of color born in the community would survive, and by association, that every mother would survive and thrive. This grassroots-style initiative is Cradle Kalamazoo. To develop the resulting program, Lubwama and her staff began by conducting surveys and interviewing mothers in the community with negative birth outcomes. With the information from those interviews in hand, they created a collaborative that represented the community and its stakeholders. Together, they defined who should be receiving services, selected evidence-based interventions, and set forth to dismantle systemic racism in the community. "We wanted to be intentional about addressing and targeting our population at risk," said Lubwama.

They used a socioeconomic framework and chose to focus on the Black population, birthing people with previous negative birth outcomes, and populations living in poverty. "We wanted to make sure we did understand our community context, especially as we address systematic racism, as we speak about systemic racism, and address racial equity and racial inequalities that exist in our community," said Lubwama. They also looked at the available social support systems within their community, questioning whether they were sufficient to address the infant mortality disparity. Lastly, they chose select individual health and behavior indicators on which to intervene. Safe sleep proved to be an important indicator, for example, so the program ended up conducting campaigns to address safe sleep practices. She and her team also started to be intentional about its home visitation program to ensure it was reaching the intended at-risk population. She noted when integrating all of these different components, social equity served as the foundation. "We wanted to make sure there was equitable distribution of resources to the population at risk, to our target populations, to the families that were most vulnerable," she said. Another focus, she added, was addressing the SDOH that can affect infant and maternal mortality and morbidity.

Lubwama reiterated that the overall goal of the program is for every Black baby and every baby of color in the community to survive their first year. This is achieved by being intentional about touching every baby born in the community, and in the process, touching their mothers, too. The end goal, said Lubwama, is to reduce the health disparities, infant mortality disparities, and all the inequities that exist around people giving birth. "That is what we have been able to implement in our community by being grassroots and being intentional," she said. In that regard, listening to the community has been critical to the program's success because it has enabled the program to be nimble and change strategies to meet the community's needs. As an example, the Cradle program started at the YWCA, and when there were proposals to move the work to health care practices in the city, community members expressed their preference for it to remain at the YWCA. Lubwama felt that this indicated that the community saw the YWCA as "an agency that understands racial justice and creates an environment in which people feel safe and valued."

# FEDERAL POLICY APPROACHES TO ADDRESS MATERNAL HEALTH AND MATERNAL MORBIDITY

The workshop's penultimate session switched gears from promising state and local interventions to policies that are being considered and implemented at the federal level, and how they can contribute to advancing maternal health equity. The session's three speakers were Jamila Taylor (The Century Foundation), Jennifer Moore (Institute for Medicaid Innovation [IMI]), and Dawn Godbolt (NBEC). Following the presentations, Kosali Simon (Indiana University) moderated a short discussion among the participants.

### The Federal Policy Landscape for Black Maternal Health

Presented by Jamila Taylor, The Century Foundation

The Century Foundation, explained Jamila Taylor, is a "progressive, independent think tank that conducts research, develops solutions, and drives policy change." <sup>52</sup> They seek to improve lives by pursuing economic, racial, and gender equity across a number of policy issues. Taylor's presentation laid out the current federal policy landscape around maternal health.

First, she grounded her remarks with The Aspen Institute's definition of structural racism as a system where public policies, institutional practices, and

<sup>&</sup>lt;sup>52</sup> See https://tcf.org/about (accessed August 17, 2021).

cultural representations work to reinforce and perpetuate racial inequity.<sup>53</sup> In the care environment, she said, structural racism manifests in health provider shortages and the concentration of lower-quality hospitals in neighborhoods populated mostly by people of color. It also manifests as racial bias and stereotyping of people of color by health care providers, and in a lack of culturally responsive care. It shows up as different treatment practices and management of pain, a practice dating back, as has been explained by other panelists at the workshop, to chattel slavery and in efforts to undermine or sabotage publicly funded health insurance programs such as Medicaid. Germane to this workshop, it shows up in the maternal mortality and morbidity inequities that so many speakers addressed.

Taylor emphasized that research suggests that racism drives poor maternal health, with the cumulative stress of racism and gender oppression undermining the health and well-being of Black birthing people. She added that these disparities are driven by "predominantly white power structures that perpetuate imbalances" (Taylor et al., 2019), as well as lack of empathy and respect for Black birthing people. In order to address maternal health outcomes, Taylor emphasized that solutions must be rooted in social justice and seek to address these inequitable power dynamics. The reproductive justice framework, she explained, was developed by Black women in the mid-1990s at the International Conference on Population and Development. It is a "human rights-based, structured approach that addresses the intersecting systems of oppression that prevent marginalized people, primarily women of color, from achieving complete bodily autonomy and parenting with dignity."54 Using this framework, it is possible to develop solutions that recognize a birthing person's ability to determine their own reproductive destiny, and that recognize that reproductive freedom is linked to the conditions within a birthing person's community. A reproductive justice framework centers solutions on women and birthing people of color and their unique experiences, and it holds that health outcomes and access to health care are central features that cannot be isolated from social issues such as economic opportunity, exposure to violence, and having safe and affordable housing.

Taylor provided an overview of several pieces of legislation that seek to address some of these factors. She noted that in the congressional session that ran from January 3, 2019, to January 3, 2021, 31 maternal health bills were introduced. In the current session, which began January 3, 2021, there have already been 26. Both totals include the Black Maternal Health Momnibus package of 12 bills that, she said, address almost every dimension of the

 $<sup>^{53}</sup>$  See https://www.aspeninstitute.org/blog-posts/structural-racism-definition (accessed August 17, 2021).

<sup>&</sup>lt;sup>54</sup> See https://www.sistersong.net/reproductive-justice (accessed August 17, 2021).

Black maternal health crisis. This package, should it pass and become law, would invest in community-based organizations, address some of the SDOH, increase the rate of maternal vaccinations, reduce the climate impacts of pregnancy and childbirth, ensure compassionate care for veterans and incarcerated birthing people, improving maternal mental health, and address other aspects of Black maternal health.

Another important bill that has been introduced is the Maternal Care Access and Reducing Emergencies (CARE) Act. This would provide funding for implicit bias training and would test innovations in integrated health services for pregnant people through pregnancy medical homes, another intervention highlighted during the workshop. Taylor noted that this was then-Senator Kamala Harris's flagship piece of legislation that she is still championing as Vice President.

Other bills before Congress seek to extend postpartum Medicaid coverage, a key solution on which maternal health advocates are focusing, and the American Rescue Plan, which did include a provision that would give states the option to extend postpartum Medicaid coverage to at least 1 year for a time limit of 5 years. She said it was important to put this last piece of legislation into context as a response to the COVID-19 pandemic, and noted that many of the provisions in the bill were not meant to be permanent. "That means the work is far from over in terms of ensuring that the continuation of postpartum coverage is permanent across the United States, in all states, for all women," said Taylor.

The Healthy MOMMIES Act, introduced in May 2019, would (1) extend coverage for Medicaid's pregnancy pathway from 60 days to 1 full year after giving birth and (2) extend coverage for eligible individuals to comprehensive care beyond just services directly related to pregnancy; this would include oral health services as well. The MOMMA's Act and the Helping MOMS Act, which have not yet been reintroduced in the current session of Congress, also aim to allow states to extend Medicaid coverage for a full year postpartum. The COVID-19 Safe Birthing Act would ensure that pregnant and birthing people could have a doula or other support person and a loved one in all health care settings. It would also expand access to maternal telehealth services for Medicaid beneficiaries, extend Medicaid and Children's Health Insurance Program coverage to 1 year postpartum, and ensure access to free testing, treatment, and vaccination for all pregnant and birthing people, regardless of their insurance status.

Outside of legislation, the Biden-Harris administration has taken other executive actions to address the crisis. For example, as Zhau mentioned in his opening remarks for the workshop, it proclaimed April 11–17 to be Black Maternal Health Week. Additionally, it has approved states' Section 1115 waivers to extend postpartum Medicaid coverage, and has increased

investments in maternal health through the American Families Plan, the president's budget, and other vehicles. The Biden-Harris administration has also placed a focus on implicit bias training, expanding maternity care among rural populations, and addressing racial inequities.

The administration also took several steps that, while not explicitly about maternal health, represent broader health care expansions that have implications for maternal health. First, the American Rescue Plan includes important health care expansions. In his first days in office, Biden signed a health care executive order creating a special enrollment period, as well as one that called for the whole of government to approach racial justice in the nation and systemic racism within government agencies. Lastly, Taylor added that she feels this administration has also been thoughtful in making its political appointments. These include installing Chiquita Brooks-LaSure as the first Black woman—and fierce advocate for maternal health—to serve as administrator of the Centers for Medicare & Medicaid Services (CMS).

In closing, Taylor offered recommendations for further actions to advance maternal health:

- Ensure mandatory postpartum Medicaid coverage for at least 1 year with generous federal matching rate increases to states, especially in light of the financial struggle of recovery from COVID-19.
- Ensure proper implementation of, beyond just passage of, laws and policies that center the health and social needs of Black women and birthing people.
- Invest in antiracism training—for both explicit and implicit bias—for health care providers.

### Medicaid and Maternal Health

Presented by Jennifer Moore, Institute for Medicaid Innovation

In the next presentation, Jennifer Moore described the challenges of access to maternal health care for Medicaid beneficiaries, and presented policy action steps for Medicaid stakeholders. IMI is a 501(c)(3) national nonprofit, nonpartisan research and policy organization in Washington, DC, explained Moore. From its inception, it has focused its work on equitable access and coverage to Medicaid, the nation's largest safety net program. Its work is used by policy makers to inform decisions that influence individuals, families, and communities and their ability to support a healthy life. This organization accomplishes its mission and strategic goals by leading work in several key areas such as women's health and equity, leading innovative initiatives that include national learning collaboratives, convening meetings with multiple

Medicaid stakeholders, and conducting quantitative and qualitative research studies.

Moore noted that when comparing maternal health systems in the United States and other high-resource countries with better outcomes, the biggest difference is the focus other countries place on midwifery-led care for all low-risk births. Digging into the data in the United States, she said, reveals glaring inequities in access to midwifery care for communities of color and especially for individuals enrolled in Medicaid. "With almost 50 percent of all pregnancies covered by Medicaid, it is important for us to consider the root causes of these inequities," said Moore.

She pointed out that while structural racism has greatly influenced the maternal health system at large, it has particularly defined the development of the Medicaid program in ways that contribute to the outcomes the nation currently faces. Moore explained that both historical racist structures and current racist policies impact Medicaid. In recent decades, there has been some expansion of federal Medicaid eligibility, which has allowed for a greater number of children and pregnant individuals to access services. However, as she noted in a recent Aspen Institute Report that she coauthored, the program continues to be hampered by policies such as

heavy paperwork requirements, frequent eligibility redeterminations, confusing and inaccessible application processes, and, more recently, work requirements to constrain enrollment and sustain a vision of the program as only being available to the "deserving" poor, with "deserving" defined as conformity to the beliefs and preferences of political leaders. (Aspen Health Strategy Group, 2021)

Because Medicaid policies are determined at the state level, there is a great deal of variation in the experience of birthing people by state. She acknowledged that "flexibility" in the implementation of Medicaid at a state level has benefits, namely in that it can allow for programs to be adapted to better address local needs. On the other hand, as she highlighted in the Aspen Report, the consequences of such flexibility are a subject of debate, especially given that the majority of Medicaid's funding comes from the federal government. The power states hold to determine their policies can also have negative consequences; as Moore wrote in The Aspen Institute report, "the neutral-sounding term 'flexibility' is often used to perpetuate policies with racist roots, akin to the invocation of 'states' rights' during the Civil War and the civil rights movement" (Aspen Health Strategy Group, 2021).

Moore said that it is important to ground today's recommendations and potential solutions in an acknowledgment of that reality. Because of this context, it is important to ensure that anything that comes out of the work on maternal mortality is inclusive of the Medicaid population. "More

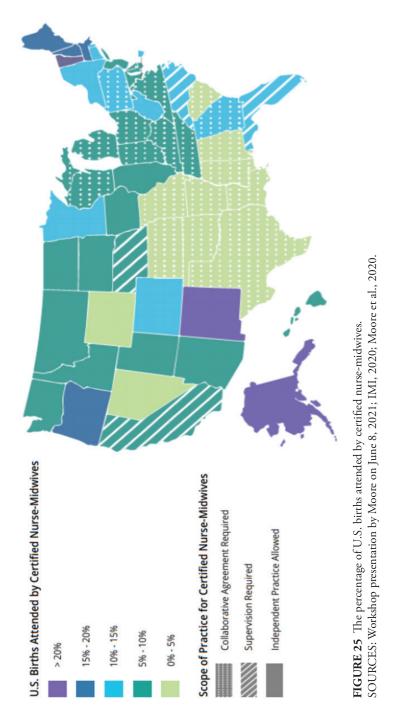
importantly, we need to remember that what works for commercially insured individuals oftentimes is not accessible for those who are enrolled in Medicaid," said Moore.

The available data reveal the rising rates of maternal and infant mortality and morbidity with significant racial and ethnic disparities, as addressed by previous speakers. In addition, health care costs are rising, accompanied by poor outcomes, and there are increasing reports of traumatic patient experiences. Almost 20 percent of infant deaths are closely linked to preterm delivery and low birthweight, with persistent disparities (Matthews et al., 2015), and for every maternal death, more than 100 women experience severe maternal morbidity (Moore et al., 2020). In addition, workforce shortages are increasing, presenting challenges for network adequacy, and there are rising unmet social needs, implicit bias, and instructional racism plaguing the U.S. health care system.

Nearly 50 percent of all births are covered by Medicaid and 70 percent of women enrolled in Medicaid are of reproductive age (IMI, 2020). As a result, there is an opportunity to focus on those served by this program to improve access to high-value, evidence-based care. She noted that there are more than 1,000 U.S. counties that do not have a single midwife, obstetrician, hospital, or birth center. A fair number of these counties, she said, are in the central and southern portions of the nation in states that have not expanded Medicaid coverage. Generally speaking, utilization of midwifery-like care is relatively low across the nation (see Figure 25) and sinks even lower when the data are stratified by payer type. Nationally, there has been a slow increase in midwifeled births; in 2020, they accounted for about 9 percent of all births in 2020.

Midwifery access and coverage is important because the data show that hospitals with midwives had a 74 percent lower rate of labor induction, a 75 percent lower rate of augmented labor, and a 12 percent lower rate of cesarean deliveries (Neal et al., 2019). Moreover, the risk of cesarean delivery in individuals who had never given birth fell by 30 percent in patients cared for by certified nurse midwives, and a nearly 40 percent lower risk of cesarean delivery in individuals who had already given birth (Souter et al., 2019). Midwifery-led care has also been shown to improve patient satisfaction scores and reduce liability claims by offering culturally congruent, respectful care that is person-centered.

Despite the overwhelming evidence demonstrating improved outcomes and lower cost, the midwifery-led model of care is underutilized in the United States. The ratio of midwives to obstetricians in the United States is 0.34, compared to 8.19 to 1 in Australia, 8.27 to 1 in the United Kingdom, and 3.46 to 1 in The Netherlands, with significantly lower maternal mortality rates in those three countries (Kennedy et al., 2020).



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The model is underutilized even more so among those covered by Medicaid. Based on extensive research at IMI, Moore and her colleagues have found that the midwifery-led model of care can be an important intervention in addressing the escalating poor birth outcomes, disparities, and racial inequities, and maternity care for the Medicaid population. "The value of midwifery-led care has been widely recognized in achieving high quality, reducing costs, improving satisfaction, and supporting network adequacy with more than 30 years' worth of evidence that demonstrate the value of midwifery-led models of care," said Moore. "It is gaining recognition as a gold-standard model."

For example, Medicaid's Strong Start initiative to improve birth outcomes, a 5-year program launched by CMS, produced significantly better outcomes for people receiving care in midwifery-led birth centers compared with matched population controls, including a statistically significant decrease in the rates of cesarean sections, preterm births, and low-birthweight newborns (Dubay et al., 2020; Jolles et al., 2019; Krans and Davis, 2014). In addition, midwife-led freestanding birth centers produced an average cost savings of \$2,010 per mother—child dyad in the first year (IMI, 2020). Importantly, focus groups conducted with Strong Start participants found them to be very satisfied with their experience.

Recently, The Aspen Institute's health strategy group released a report on tackling maternal mortality in the United States, and noted five key observations as part of its work (Aspen Health Strategy Group, 2021):

- 1. The ability of other developed countries to have lower maternal mortality rates demonstrates that better outcomes are achievable.
- 2. Midwifery-led models of care that treat pregnancy and birth as a normal, physiologic event demonstrate better outcomes than the traditional medical model (which posits birth as a pathologized medical crisis). Countries that have adopted this model as the standard of care have shown that it can be done with successful outcomes.
- 3. Racism is entrenched into U.S. models of care and policies from clinician bias to health care structures.
- 4. Current financing of maternity care is not aligned with high-value, evidence-based models such as midwifery-led care and doulas, resulting in poorer outcomes and low return on investment both from a financial and social perspective.
- 5. Under-investment in women's health as a whole, but more specifically in maternal health, is an underlying driver. This manifests in many ways, including low reimbursement from health insurers, low investment for research, and lack of paid maternity leave.

Based on these observations, The Aspen Institute's health policy group issued what it called five big ideas:

- Make maternal mortality and morbidity a priority and commit to identifying your role in improving outcomes.
- 2. Shift the maternal health care system away from the medical model and toward a community-based model where midwifery-led care is the standard for all pregnant and birthing people.
- Support a community-based model of care. To do this, the nation must align payment models both in the commercial and Medicaid markets to provide access and coverage. This includes providing continuous health care coverage and equitable reimbursement for midwives.
- 4. Racism has been entrenched into the fabric of this country for centuries, and its health care system is not excluded. To implement an antiracist culture in health care first requires developing and utilizing all the measures that incorporate concepts such as respectful and responsive care. It also requires increasing the number of leaders and clinicians from communities of color, ensuring that the voices of patients and communities are heard and represented in decision making such as on boards and oversight committees, not just advisory groups, and training everyone in the health care system on the history and manifestations of structural racism and how it can be dismantled.
- 5. Every policy and procedure within the U.S. health care system must be evaluated for bias, racism, and oppression, with efforts taken to dismantle and undertake corrective action.

Moore said that for the fifth big idea, the Aspen group noted that data on this topic, and on women's health in general, is shockingly limited. Establishing robust data collection systems and analysis, developing quality measures, leading statewide initiatives, and investing in research are all critical steps that need to be taken. "As clinicians, researchers, policy makers, and leaders, we have an opportunity to take this knowledge and lead our communities toward these goals," said Moore.

Going forward, she said, it is imperative that every Medicaid stakeholder conduct a self-assessment to identify their individual role before they can establish an action plan to support the collective effort to advance high-value, evidence-based perinatal models of care to serve all birthing people. For each stakeholder, Moore pointed to the need to look broadly outside of individual space, to identify opportunities and challenges, and to elevate the identified facilitators and mitigate barriers to achieve birth equity. She then went through a few examples specific to different Medicaid stakeholders.

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She said there are multiple opportunities for state Medicaid agencies to support birth equity. They may do so, for example, by establishing standards for equitable compensation of midwifery-led models of care, eliminating "incidence-to" billing structures, and evaluating to ensure that networks are adequately including midwives. States can also act to ensure that Medicaid enrollees have coverage for and access to a comprehensive suite of services to complement midwifery-led care, including services provided by doulas, perinatal community health workers, and other home-visiting programs.

Medicaid health plans, another important stakeholder, can make a difference in supporting birth equity by establishing equitable reimbursements for midwifery-led care. At a minimum, the services should be supported by the Medicaid fee schedule. This will support the financial sustainability of this high-value, evidence-based model. They can also engage communities and members to learn about their preferences, values, and beliefs and use that information to determine how to best position midwifery-led care as an option for their care.

Moore acknowledged that no single action or single Medicaid stakeholder will be able to make large-scale changes, but she noted that the collective actions of everyone can certainly create a movement. "Each of us knows that change is not easy," she said. "It will take every Medicaid stakeholder to address birth equity for the Medicaid program."

She also pointed out that, as the nation considers how to tackle alarming maternal mortality rates, the obvious option is to choose solutions that are already known to be innovative and cost effective. "Instead of reinventing the wheel, we can step back and acknowledge that sometimes being innovative on the cutting edge and cost effective means doing less," said Moore. "It means going back to what we know to be true and returning to our basic and fundamental understanding of birth and respecting that all people deserve an experience that is person-centered with access and coverage to the best care that is free from racism and oppression."

In closing, she said that contemporaries in other developed countries are already doing this and have far better birth outcomes. "We do not need more evidence to demonstrate what we need to do," Moore stated. "We are at a point where we simply need to do it. We cannot wait for others to prioritize women and people of color. We just have to take the lead and do it."

## **Maternal Health Advocacy Efforts**

Presented by Dawn Godbolt, National Birth Equity Collaborative

As Joia Crear-Perry noted in the workshop's open presentation, NBEC is a Black woman–led advocacy organization that provides solutions to the maternal health crisis "for Black women, by Black women." The NBEC policy group, said Dawn Godbolt, uses the reproductive justice lens that Taylor explained in order to advise elected officials, key stakeholders, and community-based organizations. Their ultimate goal is to advance birth equity through policy, practice, and programs. This reproductive justice lens, Godbolt noted, is crucial for meaningfully addressing the needs of Black birthing people.

NBEC defines birth equity as "the assurance of the conditions of optimal births for all people with a willingness to address racial and social inequities in a sustained effort." Birth equity promotes reproductive well-being, which occurs when "all people have the information, services, and support they need to have control over their own bodies and to make their own decisions related to sexuality and reproduction throughout their lives." Because different groups of people have less access to resources, birth outcomes are not equitable, as the disparities in maternal and infant health show so clearly. It is also important, said Godbolt, to understand that disparities in maternal and infant health outcomes are manifestations of racism, which is their root cause. For example, as Moore just shared, Black birthing people are more likely than white birthing people to live in maternity care deserts and as a result have difficulty accessing comprehensive reproductive health care services (March of Dimes, 2020).

The NBEC birth equity agenda includes five critical measures for ensuring that the United States has the proper infrastructure and resources in place to achieve equitable maternal health outcomes. The first is ensuring that reproductive health and autonomy are promoted and protected at the highest levels of government. Because, as Godbolt described, access to reproductive care depends on so many structural and social factors, the work of multiple federal agencies affects reproductive health. However, those efforts are often siloed, which is why NBEC has called on the Biden-Harris administration to prioritize reproductive justice.

Second, health must be a government priority and a recognized human right. The United States is the only industrial nation that does not ensure that all people have some basic level of access to health and health care. "The

<sup>&</sup>lt;sup>55</sup> See https://birthequity.org/about/birth-equity-solutions (accessed August 17, 2021).

<sup>&</sup>lt;sup>56</sup> See https://powertodecide.org/news/join-us-building-nationwide-reproductive-well-being-movement (accessed August 17, 2021).

COVID-19 crisis drew a devastating picture of how disparities are manifestations of racism and how widespread health and economic consequences affect all of us when public health is de-prioritized," said Godbolt.

Third, individual and institutions should be held accountable for discrimination that leads to disparate health impacts. NBEC believes that the federal government should support health care transformation efforts that include health equity as an explicit goal, that are grounded in the needs of communities of color, and that seek to provide care that is equitable, trauma informed, reflective of the health care needs of communities of color, and include a fully integrated reproductive health care agenda. The federal government should also prohibit laws, policies, and practices that cause preventable inequalities in health outcomes, regardless of their intent.

Fourth, no maternal death should go unnoticed or uncounted. Despite decades of rising maternal mortality and morbidity, the United States does not collect and disseminate reliable and timely data on maternal health. "The government should require and support all states and U.S. territories to collect and disseminate maternal mortality and morbidity data disaggregated by race and ethnicity," said Godbolt.

Fifth, government involvement in reproductive health should not intrude on reproductive freedom, agency, and autonomy. This idea hearkens back to the reproductive justice tenets previously referenced. Government involvement in reproductive health can advance human rights by ensuring that all people have access to health care services that enable them to prevent and treat illness, experience the best health outcomes possible, and, crucially, to make the reproductive decisions that are right for them.

NBEC has worked on several projects to achieve these goals. For one, NBEC has promoted and developed models of respectful care. The NBEC model, which Crear-Perry described in her opening presentation to the workshop (Green et al., 2021), is based on themes and data collected from Black mothers in cities across the United States. Themes in the framework include accountability, equity, empathy, safety, antiracism, and trust. The model is deliberately cyclical, because the path to respectful care is iterative and has to be replicated at the interpersonal, individual, and institutional levels.

One example of NBEC's community-based advocacy work is the Maternal Health Access Project, a collaborative effort with six other partners.<sup>57</sup> The project was designed to increase access to perinatal services and supports via telehealth, increase capacity of maternity care providers to delivery care via telehealth, and disseminate Web-based information and public service

 $<sup>^{57}</sup>$  This study and its outcomes are described in more detail in Nia Mitchell's presentation, from the first day of the workshop.

announcements. Godbolt said NBEC was charged with carrying out a needs assessment via listening sessions and developing a request for proposals to disperse funds to community-based organizations as part of the implementation phase of the project. She noted that 15 organizations received funds from the project to enhance the telehealth infrastructure for maternal health services provided by doulas, nurse midwives, and childbirth education services to Black birthing people across the country and U.S. territories. Over the course of this project, NBEC developed several recommendations for increasing access to telehealth services:

- Allocate additional and sustainable funding to Black women–led community-based organizations to support the delivery of care via telehealth and make culturally appropriate care available to Black communities.
- 2. Support trauma-informed, racial equity—based telehealth training for providers.
- 3. Subsidize telehealth services for pregnant and childbearing people as patients continue to shift to telehealth services as an alternative to in-person visits.
- 4. CMS should support hybrid models of health care by providing guidance, incentives, and promoting telehealth services. By offering hybrid models of care, birthing people would have access to alternative care models and can decide for themselves which avenue of health care is most appropriate.
- 5. Invest in developing patient record systems that prompt for social service direct referrals when necessary. Robust interoperable record systems can be used to support patients and coordination with continuity of health care.
- 6. Embed a model of respectful care within maternal care and track quality improvement metrics to provide accountability mechanisms.

Another project in which NBEC is involved is a public–private partnership led by HHS that aims to close gaps in maternal health outcomes as measured by severe maternal mortality, severe maternal morbidity, and the rate of cesarean births among low-risk, first-time mothers. NBEC convened a stakeholder group that included predominantly Black maternal health experts, policy people, midwives, doulas, obstetricians and gynecologists, lactation consultants, and mental health specialists. Key themes that emerged from what Godbolt called robust discussions included racism; accountability; data transparency; financial incentives; collaborative, multiexpertise team approaches to maternal health care delivery; systems approaches and policy

change; person-centered care; and centering Black leadership in the maternal health space. Recommendations that came out of these discussions focused on changing the relationship dynamics between patients and providers, modifying hospital systems' behaviors, and generating accurate data disaggregated by race. Godbolt said she is excited to see what the outcomes of this project will be over the next year and a half.

A third example of NBEC's work in the policy area involves its advocacy for the creation of a White House Office of Sexual and Reproductive Health. "We believe that sexual and reproductive health should be prioritized at the highest offices of government, including the White House," said Godbolt. The reasoning here, she explained, is that, as previously mentioned, many of the federal efforts to address maternal health are siloed in nature; and this is a disservice to Black and brown communities across the country that have historically been barred from accessing the health care services they need. She noted that there is broad cross-sector support for the development of this office, including support in both chambers of Congress and more than 150 different organizations that represent the maternal and child health field and the reproductive justice movement. If established, the Office of Sexual and Reproductive Health would develop a national sexual and reproductive health strategy that would include a framework for integrating sexual and reproductive health equity into federal processes. It would also oversee an intergovernmental workgroup on sexual reproductive health and well-being. The office would identify areas of improvement in federal rulemaking and guidance, provide recommendations, and lead public engagement activities, including public listening sessions and White House conferences on sexual and reproductive health.

In closing, Godbolt said there is no one policy solution that will comprehensively address the maternal health crisis, but the recommendations that she and the other speakers at this workshop have made are steps in the right direction. Godbolt said.

Black mothers and Black babies deserve respect, autonomy, and choice, and we also deserve access to social supports and benefits that allow us to collectively participate in the everyday joy of life. For too long, too many of us have been underserved by a system that does not value our lives. It is time for our government, our policy makers, our health care system, and our health care providers to meaningfully meet the needs of our communities by listening to more Black women so that more Black mamas and babies can thrive.

### Discussion

The first questioner from the audience asked if the speakers feel that provider-centric electronic health record systems currently available—and used widely due to the Health Information Technology for Economic and Clinical Health Act—are adequate for the data collection and monitoring needed to improve maternal care, or if a patient-centric system would work better. Moore noted that there is a platform called Maternity Neighborhood<sup>58</sup> that was developed by a midwife and that is very person-centered. Moore said she has used it as a patient, and it enabled her to speak with a midwife or an obstetrician-gynecologist and have control and agency over her health records. Godbolt added that as our health system shifts to include more telehealth, many adjustments will need to be made to records.

Simon then posed a question from the audience that asked the panelists to comment on the Mothers and Newborns Success Act, sponsored by Senators Tim Kaine and Lisa Murkowski. Taylor said that the bill had not yet been reintroduced in the current congressional session, and that she would follow up with Senator Kaine's office as to its status.

The next question asked about the importance of racial concordance in midwifery, noting that while panelists had highlighted the importance of midwives, 90 percent of midwives in the country are white. The audience member asked whether race mattered if the midwives provide quality care. Moore replied that it is important for individuals to receive care from people who look like them, who come from communities like theirs, and who can relate to them. She believes it should be a national priority to ensure that there is sufficient representation among providers to support respectful and culturally concordant care for pregnant and birthing individuals. Moore also noted that, in her opinion, when she underscores the value of midwifery, she is speaking about more than just increasing the number of practicing midwives; she is also speaking about promoting the midwifery-led model of care more broadly. Moore said,

We know of obstetrician-gynecologists, family practitioners, and midwives who all practice around this model, and I would extend the question to go beyond midwifes and look at the family practice doctors who are in this space to ensure that they come from communities and look like those whom they are serving.

Godbolt agreed, pointing to the many studies that demonstrate that having a provider that looks like their patients does improve outcomes, particularly

<sup>&</sup>lt;sup>58</sup> Additional information is available at https://maternityneighborhood.com (accessed August 15, 2021).

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for Black birthing people and Black infant mortality rates. She also remarked that the Black community has a historical tradition of midwifery care that was eliminated at the beginning of the 20th century along with the workforce. "In the same way that we deliberately got rid of that workforce, we can rebuild that workforce," she said. Godbolt also noted that expanding pathways for birth workers of color is a core component of most of the policies for which NBEC advocates. One proposal would be to establish midwifery programs at the medical schools associated with Historically Black Colleges and Universities. "That would be a very easy lever to pull to increase access to midwifery care," said Godbolt.

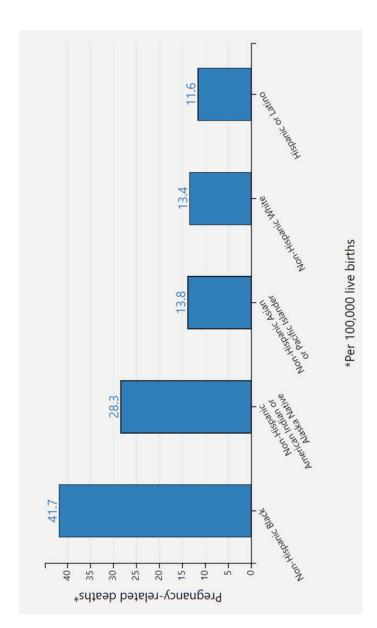
## RESEARCH AND FUNDING NEEDS TO INCREASE KNOWLEDGE GENERATION AND IMPROVE MATERNAL HEALTH OUTCOMES

The workshop's final session focused on looking forward, to how to advance the area of maternal health equity. Specifically, it focused on how research and funding mechanisms might help to develop a deeper understanding of the issue and achieve the desired outcomes that the workshop's presentations and discussions had highlighted. The four speakers in this session were Juanita J. Chinn (National Institute of Child Health and Human Development [NICHD]), Kathryn Schubert (Society for Women's Health Research [SWHR]), Monique Shaw (Robert Wood Johnson Foundation [RWJF]), and Tenesha Duncan (Tara Health Foundation).

# National Institutes of Health-Supported Maternal Mortality Research and Opportunities

Presented by Juanita J. Chinn, National Institute of Child Health and Human Development

In April 2021, NCHS published the most recent official statistics for U.S. maternal mortality. It showed that there were 20.1 maternal deaths per 100,000 live births in 2019. Juanita Chinn noted this was a statistically significant increase from the 17.4 maternal deaths per 100,000 live births in 2018 (Hoyert, 2021). As has been the case for years, Black and Indigenous people continue to be affected disproportionately and carry the burden of maternal mortality in the United States. What we know about infant mortality in the Pacific Islander community, she noted, "suggests that they are also disproportionately impacted by maternal mortality and thus underscores the need for disaggregated data" (see Figure 26). The CDC data on the leading



SOURCES: Workshop presentation by Chinn on June 8, 2021; https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-FIGURE 26 Pregnancy-related mortality by race and Hispanic origin, 2014–2017. surveillance-system.htm#trends (accessed August 15, 2021).

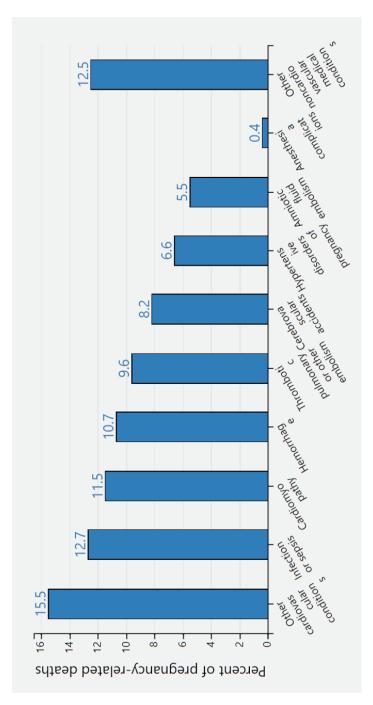
cause of pregnancy-related deaths for all birthing people include "other" cardiovascular conditions, infections or sepsis, cardiomyopathy, and hemorrhage (see Figure 27).

When MacDorman and colleagues (2021) examined text found in death records to identify potential missed or misclassified information, including maternal deaths, the findings showed that Black/white disparities in maternal mortality may be even greater than reported. This analysis found that the excess maternal deaths for Black people were concentrated in a few clinical causes of death: eclampsia/preeclampsia, postpartum cardiomyopathy, obstetric embolism, and ectopic pregnancy.

Chinn noted that severe maternal morbidity provides a window of intervention opportunities for maternal mortality. Data from California, a state that has experienced declines in adverse maternal outcomes overall, have shown that racial and ethnic disparities in severe maternal morbidity have both persisted and increased (Leonard et al., 2019b). The known risk factors for severe maternal morbidity do not fully account for increases in disparities, nor do the changes in the prevalence of these risk factors fully account for the changes in severe maternal morbidity and ultimately mortality (Leonard et al., 2019a). "If these factors do not fully account for the changes observed in severe maternal morbidity rates, the researchers must also examine nonclinical factors as well," said Chinn.

As other speakers throughout the workshop had noted, Chinn said that access to quality care is critically important for reducing maternal mortality and morbidity. Data from New York City show that birthing people from racial and ethnic minority groups give birth in hospitals with lower overall quality and higher rates of severe maternal morbidity (Howell and Zeitlin, 2017; Howell et al., 2020). Moreover, Black and Latinx people giving birth in low-performing hospitals report "poor patient–provider communication, trauma, and difficulties in obtaining appropriate prenatal and postpartum care" (Chinn et al., 2020). Data from Louisiana also reveal a link between maternity care deserts and pregnancy-associated mortality, with a 2.2-fold higher risk for non-white individuals above and beyond differences in geographic access to maternity care (Wallace et al., 2021).

Chinn added, these data also reveal that homicides accounted for more deaths of pregnant and postpartum women than any single obstetric cause (Wallace et al., 2016, 2020). The risk of dying by homicide was highest for women and girls ages 10–29, and pregnancy-associated homicide was three times higher for non-Hispanic Black women than for non-Hispanic white women nationally. Homicides can have indirect effects as well. In fact, Rachel Hardeman and her team at the University of Minnesota are conducting research involving women in and around Minneapolis after the police shooting of Philando Castile and Thurman Blevins. They have found that more than



SOURCES: Workshop presentation by Chinn on June 8, 2021; https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-FIGURE 27 Leading causes of pregnancy-related mortality, 2014–2017. surveillance-system.htm#trends (accessed August 15, 2021).

half the women surveyed answered "yes" when asked if they felt that news was affecting their current pregnancy.<sup>59</sup>

With this context in mind, said Chinn, NICHD published a strategic plan<sup>60</sup> in 2019. The future research directions that they identified prioritized maternal health and included an emphasis on health inequities and preventive medicine. In the same year, NICHD convened two workshops, one a future directions meeting and the other a community engagement forum, to inform the maternal health research agenda. Racism, said Chinn, was a theme that resounded throughout both workshops regarding research clinical gaps and policy opportunities (Chinn et al., 2020). She also noted two ongoing studies related to pregnancy and the COVID-19 pandemic, one of which—Gestational Research Assessments for COVID-19—has already shown that pregnant people were at higher risk of severe disease, including hospitalization, need for ICU care, and medical ventilation with COVID-19.

The National Institutes of Health (NIH) is currently leading a project to develop an implementation guide for data linkages between multiple maternal electronic health records and infant electronic health records and vital records. The goal, said Chinn, is that this will facilitate research on pregnancy, pregnancy outcomes, and pregnancy-related conditions, comorbidities, and procedures. Meanwhile, the Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone initiative is funding research through NICHD and other NIH institutes aimed at reducing preventable causes of maternal death and improving health for birthing people before, during, and after delivery. A critical goal of this initiative, said Chinn, is to resolve health disparities and attain equity in maternal health.

Another program supporting research is the Addressing Racial Disparities in Maternal Mortality and Morbidity run by the National Institute on Minority Health and Health Disparities. The NIH Centers of Excellence on Environmental Health Disparities is helping centers at the Baylor College of Medicine and the University of Southern California to focus on maternal health. Both of these centers will engage the community and researchers; they will use interdisciplinary collaborations to understand the contributions and cumulative effects on maternal and infant health outcomes that result from exposures in the biological, physical, social, and built environments during and after pregnancy.

In closing, Chinn said she and her colleagues at NICHD are excited

<sup>&</sup>lt;sup>59</sup> For more information, see https://www.npr.org/2020/11/13/933084699/how-police-violence-could-impact-the-health-of-black-infants (accessed August 15, 2021).

<sup>&</sup>lt;sup>60</sup> See https://www.nichd.nih.gov/sites/default/files/2019-09/NICHD\_Strategic\_Plan.pdf (accessed August 15, 2021).

<sup>61</sup> See https://www.nichd.nih.gov/health/topics/factsheets/maternal-morbidity-mortality#f10 (accessed August 17, 2021).

about the work currently being done and looking forward to the work that they expect to see in the pipeline. She added, lastly,

to substantially move the needle in reducing and eventually eliminating racial disparities in maternal morbidity and mortality and racial disparities in health more broadly, it is critical for us to understand the impact of institutional policies, inclusive of racism and health.

# Increasing and Sustaining Investment in Research to Optimize Health and Outcomes

Presented by Kathryn Schubert, Society for Women's Health Research

To start her presentation, Kathryn Schubert explained that SWHR was founded more than 30 years ago to address the lack of inclusion in research of women. Today, SWHR promotes research on biological sex differences and women's health through science, policy, and education. She noted that, ultimately, research is one part of the puzzle to addressing maternal mortality and morbidity and the inequities that birthing people of color experience; a combination of coverage, access, cultural, and societal support will need to accompany research. Nevertheless, in her view, there is a great need for increased focus and resources to be given to cross-agency research. This will help increase the knowledge base and improve maternal health outcomes.

Currently, the majority of investment for such research occurs at the federal level. Chinn summarized some of these opportunities. Schubert said that one of the challenges to growing this research is that there is little incentive for private investment or industry to do this work, and too many potential funders see pregnancy as a short-term issue and a life stage, which perhaps has less appeal than tackling a disease.

Using data from NIH's Research Portfolio Online Reporting Tool, Schubert found that the majority of NIH funding for maternal mortality research comes from NICHD, while the majority of research funding on women's health in general comes from the National Cancer Institute, followed by NICHD; the National Heart, Lung, and Blood Institute; the National Institute of Diabetes and Digestive and Kidney Diseases; the National Institute on Drug Abuse; and the National Institute of Mental Health. She noted that CDC, the Food and Drug Administration, the Agency for Healthcare Research and Quality, and the Administration for Children and Families also support women's health research. There is also the Office of Research on

<sup>&</sup>lt;sup>62</sup> See https://swhr.org/swhr-applauds-congress-for-supporting-funding-for-nih-office-of-research-on-womens-health (accessed August 17, 2021).

Women's Health at NIH, which is not an institute, but it is "the first public health service office dedicated specifically to promoting women's health research within and beyond the NIH scientific community." <sup>63</sup>

Schubert pointed out that of NICHD's \$1.37 billion budget in fiscal year 2017, 14 percent went toward pregnancy and maternal health research, compared to 55 percent of its budget that was targeted to pediatrics. Most of the research on pregnancy and maternal health was directed at preeclampsia, with smaller amounts to obesity in pregnancy, gestational diabetes, and depression. She also noted that looking at pregnancy and maternal health research by broad scientific domain shows that most went toward basic research, followed by behavioral interventions, population health, biomedical interventions, and then screening and diagnosis.

As she noted in the introduction to her presentation, women were historically excluded from clinical research, a situation that extended into the 1990s. While SWHR and the Office of Research on Women's Health have raised the levels of participation of women in research, it still lags behind that of men. Additionally, subpopulations of women in research still do not reflect the overall U.S. population today. Specifically, including pregnant and lactating individuals in research is still considered off limits in much of the research world. Schubert said,

We truly need to remove those barriers to be able to learn more information about how to improve outcomes, not just for mom and baby, but also when you are thinking about women's health across the lifespan and what is going to happen later on.

Ultimately, she added, the goal is to move from a culture of exclusion to one of inclusion. Doing so, she said, will require acknowledgment that structural racism exists. It will also require serious work to build trust, and to create where people feel safe and willing to participate actively in research.

Schubert said that Porchia-Albert's earlier remark that "postpartum is forever" resonated with her, and that it is something to consider when thinking about investments in research. "It is not just for better maternal health outcomes during that period of time in a person's life when they are of child-bearing age. It will improve outcomes for a woman's life across the lifespan," she said. "It will also inform maternal health prior to pregnancy."

What is needed, she said, is increased and sustained investment in research to optimize health and outcomes for both mother and child, as well as basic, translational, clinical, and public health services and policy research, along

<sup>63</sup> See https://orwh.od.nih.gov/about/mission-history (accessed August 17, 2021).

with implementation science. "If we want to impact maternal mortality and address the health equity issues facing women in this country, we need to invest in research in women's health throughout the lifespan and through a health equity lens," said Schubert. That research, she added, must be patient-centered and multifaceted. It must look at the effects of conditions, diseases, and life stages on past and future health, and it must include life transitions across health data systems and settings. Lastly, it should ensure the inclusion of pregnant and lactating individuals in trial designs.

Schubert said in closing that her call to action is a comprehensive, collaborative, large-scale initiative that would provide significant investment to tackle these issues. Ultimately, though, the bottom line should be that women need to be valued and prioritized in this country, in research and elsewhere, to be able to move forward and address the maternal mortality crisis.

## Funding Priorities at the Robert Wood Johnson Foundation

Presented by Monique Shaw, Robert Wood Johnson Foundation

Monique Shaw began her remarks by noting there are several opportunities for the Robert Wood Johnson Foundation to engage in and address—issues stemming from the glaring disparate outcomes in maternal health. She reiterated that these are rooted in systemic and structural racism and perpetuate conditions where birthing people, particularly birthing people of color, lack access to quality, affordable, culturally appropriate, respectful, and relevant care.

The foundation does not have a specific strategy that focuses on maternal health at this time; however, in recent years it has initiated discussions with grantees, field experts, and other funders in order to gain insights about the role of maternal health and well-being in achieving an overall "culture of health," which is a foundation priority.

Shaw added that while the foundation began to feel a sense of urgency to respond to the maternal health crisis, a more significant impetus to work in this field was that it observed that its grantees were shifting their priorities to work on addressing the inequities that previous speakers have addressed. "This helped to illuminate for us the direct linkages and natural alignment of the work of our grantees and partners to our existing priorities and strategies that focus on health care system transformation," said Shaw. As a result, the foundation began to see how the strategies it applies to its other goals—such as enhancing the health care system's capacity to meet patient's goals, and dismantling structural racism in the nation's health care system—could make a difference for maternal health as well.

ADVANCING MATERNAL HEALTH EQUITY

Shaw highlighted a few examples of funding opportunities relevant to improving maternal health. Currently, for example, RWJF is funding an effort that involves the National Alliance to Impact the Social Determinants of Health (NASDOH) and the National Partnership for Women & Families and its maternal health expert advisory group, Raising the Bar. This effort is using a highly collaborative process to develop principles that set a high standard for transforming the health care system to advance health equity. The project includes a focus on creating guidance for how to bring those principles to life within the context of maternal health, and to change systems to reduce racial disparities in maternal morbidity and mortality.

RWJF is also working in the measurement space. It is funding some of NBEC's work to create a validated patient-reported experience measure and to integrate the patient's voice, community advocacy, and provider training into the development of respectful maternity care practices. They are now also working with researchers at Johns Hopkins University to validate a survey measurement for respectful care that will be included as part of the patient's discharge survey at four pilot hospitals across the United States. She emphasized that in order to build the evidence to reduce inequities, Shaw said, it is essential to identify what health care and policy research questions are important to Black, Indigenous, and other birthing people of color.

Additionally, in that vein, RWJF is supporting its grantees in the Policy and Systems for Action programs, some of which have portfolios relevant to this work. For example, some are looking at structural factors that adversely affect reproductive health outcomes, state policy levers and solutions to advance women's health equity, and the implications of state-level contraceptive policies for preventive health utilization. Another is examining the differences in local laws and regulations to help better understand the impact of investing in infrastructure and a health-in-all-policies approach to improving outcomes.

The foundation, along with many other funders, is also supporting a nationwide study of the impact of COVID-19 during and after pregnancy. The study is looking at a racially and ethnically diverse group of birthing people and their babies across a variety of practice settings in the United States. Toward that end, RWJF has provided support to ensure that authentic community engagement is present across all study activities, including the recruitment process, in choosing study questions and goals, and in disseminating study results.

For more than 20 years, the foundation has invested in community power building, and more recently in increasing community power to advance birth justice. The foundation views building power within communities as essential to the health and well-being of people who have endured decades of racial injustice, economic exclusion, social marginalization, and health inequities. Community power, said Shaw, takes advantage of the ability of people most affected by inequity to create change through their strengths. Shaw said,

We are exploring ways in which we can help build and increase community power by supporting the development, growth, and sustainability of organized groups of people with diverse perspectives and lived experiences who act together through democratic structures to set agendas to shift public discourse and to influence who makes decisions.

This work of increasing community power to advance birth justice is being carried out by three organizations—SisterSong, the Groundswell Fund, and the Ms. Foundation for Women—each of which is deeply committed to providing the technical assistance to help build the capacity of community organizations to help increase their base, deepen their networks and coalition-building processes, amplify their voices, and collectively advance their mission across intersectional issues.

In Shaw's view, these and other projects with which RWJF is involved can help to build a cohesive story on issues related to maternal health. This will enable the foundation to advance its work on transforming systems with a stronger narrative, one that centers racial equity and the voices of those most affected, including people of color. The foundation also understands, though, that birth equity cannot be achieved with health care system transformation alone. "We are working to identify the multiple strategies and approaches and multiple levels that should be and need to be employed and that we can support through our funding," said Shaw, "including building the evidence, the narrative change work that is necessary, the community power work, and work to support and amplify the voices of leaders to realize the changes that we want to see, which is that people, their children, their families, and communities are thriving."

Shaw noted that RWJF's investments aimed at advancing birth equity have helped strengthen its work across all of its priority areas and to advance its overall vision of a culture of health. "We are humbly excited to engage and support the work in this space, knowing that we are very new to this space," said Shaw. She also said in closing that the foundation is looking introspectively at interrogating its own funding practices to make sure that its programs are part of the solution and are not furthering inequities and disparities.

# Paradigm Shifts for Funders

Presented by Tenesha Duncan, Tara Health Foundation

In the workshop's final presentation, Tenesha Duncan started by restating the definition of birth equity developed by NBEC and by providing a definition for birth justice, which several speakers had mentioned during the course of the workshop. Birth justice, she explained, is a movement that believes that "when birthing people recognize their innate power to make the best health decisions for themselves and their families during all stages of the pregnancy, birth, and post-birth period, that power will have a transformational impact on their family and community." These definitions, she said, help get to the root of for whom, with whom, and what outcomes are on the table for discussion.

Duncan said,

We see from these definitions that what Black, Indigenous, and people of color are seeking, whether they be the pregnant person, the birth workers, community-based organizations, or people in large institutions who operate with this frame, goes well beyond the clinical metrics we have long used to drive the research and funding conversation.

That idea, she said, does not devalue clinical outcomes, so long as they are paired with an interrogation of the issues that cause them. People, she said, want more than just to survive pregnancy, and they deserve that. "Sovereignty and self-determination are the outcomes that we are seeking when we talk about pregnancy, birth, and health outcomes over the life course," she stated.

As a funder, the Tara Health Foundation organization starts from the perspective of three paradigm shifts that acknowledge the role of racism, sexism, misogyny, white supremacy culture, and how those create challenges for people within those institutions that are trying to advance birth equity and justice. The first paradigm shift requires an institutional reframing. Duncan said that dominant culture systems are not designed to support the work of eliminating inequities; thus, institutions have to be willing to do the internal work to address blind spots and change processes so as to affect the deployment of resources, the strength of collaborations, and the shift of power and assets to the field. "We created these systems and we can and must change them, but willingness is the key," said Duncan.

The second paradigm shift requires a willingness to fund this change. It requires that funders listen to partners, and ask how a potential grantee institution has done the work, who it values as partners, and what they value as expertise. Funders must consider how they perpetuate inequity systems of power by not making space at the table. "We have to fund the people who are shifting us from just a frame of diversity, just clinical outcomes, and from this frame of death to the folks who are sharing what is working, what is addressing root causes, what is actually building power," said Duncan. "That means listening to and amplifying new leaders beyond any sort of tokenism, but really creating inclusive spaces for people to be at the table."

<sup>&</sup>lt;sup>64</sup> See https://voicesforbirthjustice.org/birth-justice (August 17, 2021).

The third paradigm shift is an acknowledgment and understanding of economic justice, the role that underresourcing plays not only for access for pregnant people, but also for the people who are delivering care to them. Underresourcing, Duncan explained, is an issue that affects all of the conditions in which care is accessed and provided. Giving funds without restriction, she said, builds power in critical ways. There must be funding support for Black and brown people and their families, as well as leaders and organizations in the field.

Her foundation's approach to funding research is through the framework of research justice. Research justice, said Duncan, starts with self-determination and understanding that data and research are currencies that build economic, cultural, and political power; they allow people to increase the knowledge in the community, shift narratives, and improve outcomes. Research justice acknowledges that systemic racism is inextricably linked to care quality, outcomes, funding, and how research priorities are set. Finally, research justice requires having resources for capacity and infrastructure building to produce long-term change and impact. Research justice is loosely related to birth justice, in that it addresses the questions of what care and experience people want, who provides them with that care and experience, and who has access and power in the receipt and provision of that care and experience. In practice, research justice serves as an expansive model that reflects some of the gaps and opportunities and the interconnectedness of issues along this continuum of research (see Figure 28).

Currently, the Tara Health Foundation's work focuses on expanding local pilots to national academic research through a wide range of partners. They use a model to help support this work (see Figure 28). Their programs start with capacity building, which specifically aims to support community-based organizations to engage in community-based participatory research. The foundation is also working on revising training and education in clinical settings, to determine what it looks like to have antiracist, justice-informed, culturally competent care models and how to teach them effectively. They fund workforce and leadership development, in order to create pipelines, pathways, and places for perinatal care providers and to start understanding what investment is needed to create a critical mass of leaders. They also focus on driving a culture and narrative shift. Specifically, they are elevating team models, touting the power of midwifery and doula care, and working to name and dismantle racism and name the importance of cultural concordance and humility as drivers of better outcomes. The foundation also supports quality improvement efforts that seek to measure and dismantle systemic and institutional racism in care; they do this by supporting quality improvement by building research that centers the experiences of Black people. The final area of emphasis is on building community birth infrastructure.



**FIGURE 28** An expansive model reflecting the gaps, opportunities, and interconnectedness of issues along the research continuum.

SOURCE: Workshop presentation by Duncan on June 8, 2021.

To conclude her remarks, Duncan briefly described some of the organizations the foundation is supporting, including the SACRED Birth, PRIORITY, and Shades of Blue Project studies that Scott, Gaw, and Matthews, respectively, spoke about during the first day of the workshop. They also support the BElovedBIRTH Black Centering Project, which honors and celebrates Black birth, Black families, and Black community and allows people to have access to a Black team of health care providers, family support advocates, doulas, breastfeeding specialists, doctors, and nutritionists. Another project they funded developed the IRTH app, which allows birthing people to connect with each other to share their experiences in health care settings; it aims to empower them to choose where they birth, who their clinicians are, and to understand the hospital or clinical setting that they might enter.

Together, these projects span a range of topics that are centered on birth equity, birth justice, and economic justice. As a closing note, Duncan stressed

that funders will need to examine their funding structures and systems in order to better support this type of work.

## Discussion and Concluding Remarks

Claire Brindis opened the discussion by asking the speakers to discuss the role of structural racism in conducting research and how to address it. Duncan replied that, from the very outset, attention should be paid to who is conducting the research, who is on that team, who is in the room—do they understand the frameworks that need to be included in this type of research? In her opinion, the PRIORITY studies are a beautiful example of what it looks like when research moves beyond just understanding the demographics of Black and white, and instead focuses on understanding the experience of a Black person accessing pregnancy care and in the midst of the COVID-19 pandemic. Chinn added that research from NIH has shown how structural racism can affect the types of research that are prioritized and how it can affect the research itself. For example, they found that there has been less emphasis on funding health inequities research, and what research has been conducted has largely been by researchers of color (Hoppe et al., 2019). Structural racism, she added, can also create bias that affects the review process for grants and publications (Ginther et al., 2011).

The next question asked the speakers to identify the biggest gaps and data needs in the field that need to be filled to advance equitable, high-quality care for all birthing people. Shaw said she thought it important to identify gaps in funding regarding the factors that influence whole-person care in the perinatal and postpartum periods, including mental health, immigration status, intimate partner violence, housing instability, and the health and well-being of other children in the family. "It is important that we fund these efforts in an intersectional way because the more that we continue to fund equity work in silos, the more fractured the ecosystem becomes and then we are less effective at improving conditions," said Shaw.

Schubert agreed that if studies are not looking at the environment that someone is in and what kind of supports that they need, the findings will not help improve maternal health and infant health outcomes. To this end, she stressed the importance of overlaying data sets. She also called for more research on transitions of life stages. For example, it would be useful to understand how best to transition a person back to their primary care provider from their obstetric care provider and what information and knowledge they need to bring with them, and even how COVID-19 might affect that.

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Another questioner asked about the value of real-world data<sup>65</sup> and if that is something that can be helpful to maternal and child research. Schubert said that SWHR utilizes real-world data often, and called for exploration of how they can be used to identify what people value in their care experience and the outcomes that are important to them. Real-world data could prove valuable for answering questions about the quality of life people want and the barriers they are encountering that keep them from having the outcomes they desire.

An audience member asked the speakers to talk about what challenges might arise in trying to fund the types of research that they described, compared to more traditional research. Schubert responded that it can be difficult to secure funding because there may not be an obvious profit incentive, which has at least been a challenge with attracting federal and industry funders. She said that it will be important to continue to amplify community voices that advocate for this type of research to get the support it needs. Chinn agreed, and said that the more recent allocation of funds toward the topic of maternal health at NIH—including outside of NICHD—is evidence that the voices of advocates and the community are being heard. Duncan said that even including the word racism in a grant proposal can cause it to be eliminated from consideration. She also said that review committees in funding spaces often do not have people on them that understand this work and its importance. "You have a real incongruence with the researchers in the field and the people who are making the decisions about funding and what kind of support they are able to receive," said Duncan. Another barrier, she said, arises in the way institutions prioritize this work over others within the hierarchy that exists in academia.

Another audience member asked a question about racial and cultural concordance, asking the panelists to discuss the intricacies of how to assess whether someone is racially or culturally concordant. Chinn, responding first, said that the question is very complicated. She feels that when thinking about the individuals reviewing research applications, cultural concordance is one of several important factors that should be considered. She also emphasized the importance of ensuring that the evaluators, whether at funders or at journals, have a background in the particular science, methodology, and theoretical framework and motivations of the proposed research.

For the final question, Brindis asked the speakers to talk about how

<sup>&</sup>lt;sup>65</sup> According to the Food and Drug Administration, real-world data are the data relating to patient health status and/or the delivery of health care routinely collected from a variety of sources, including electronic health records, claims and billing activities, product and disease registries, patient-generated data including in home-use settings, and data gathered from other sources that can inform on health status, such as mobile devices. Additional information is available at https://www.fda.gov/science-research/science-and-research-special-topics/real-world-evidence (accessed August 15, 2021).

advocates can work to ensure that maternal and child health equity be prioritized in the broader health research agenda. Schubert said that voices of advocates, community members, and individuals over the past few years have enabled the very conversations that have occurred at the workshop. "Thank you to all of the people who have participated in this workshop and beyond because without your voices, we would not be as far as we are," said Schubert, who encouraged everyone to keep talking about these issues and engage with policy makers. She called for attendees and presenters to think about how to continue empowering researchers and clinicians to engage on these issues. From an organizational perspective, she said coming together with the same message is important. She noted the rising number of women in positions of political power, both in Congress and in the administration, and said this is the time to keep pushing these issues and asking for more support, more resources, and more attention to the matter of maternal health equity.

Shaw added that advocates have a crucial and essential role to play in pushing an agenda for change. She asked, however, that advocates not only elevate the problems faced by birthing people, particularly those of color, but also elevate solutions and the assets these communities have. Shaw said,

When we focus solely on the problems and do not identify the solutions and the assets that are based in the community and that are really pushed forward by community-based organizations and leaders in the community, it impedes the dollars from being directed toward advancing evidence-based solutions that have been identified by the community and reinforces the complex nature of the problem as being one that is too large for anyone to solve.

To conclude the meeting, Brindis offered a few of the themes she heard over the workshop's 2 days. She noted that she has been in this field for almost 50 years and it has been a gratifying opportunity to see the tremendous growth and the voices she is listening to now that were never raised in her earlier career. "I am very optimistic about where we are heading," she said. Brindis also acknowledged that 2 years ago, when the idea of holding this workshop first came up, it would have been impossible to anticipate the tremendous historical moment in which these discussions have been held and the historical confluence between the pandemic, the murders of so many community members, and the call to action. "In some ironic ways," she said, "the fact that this baby took a little while longer to come to birth has probably contributed to our ability to bring the diverse voices that we have all so well benefited from over the many topics that we have covered."

One theme she identified had to do with the kaleidoscope of these issues. "There are so many different complexities, so many different levels, and depending upon how you turn your kaleidoscope, you see different vantage points in different ways," said Brindis. "For me, over and over again, we heard

the importance of putting the woman's voice and her experiences throughout her life course in the middle of that kaleidoscope."

She also provided a visual of a "microscope" to connect the presentations. The microscope, as she described, took the discussions deep into important topics and then used a wider lens, depending on whether an activity was occurring in a particular tribal group, a particular hospital, at the state level, at the funder level. "All of these elements within our microscope and kaleidoscope have to be brought together," she said.

A third image she gave was of the story of the stone soup, which is that each person alone cannot make progress without each other. Brindis said,

While we each may be limited by some of the resources that we have in our own cupboards, coming together and sharing resources will create this very nourishing, low-fat, healthy, nutritious broth that I think will continue to leverage each other's efforts. It was so wonderful to hear about the interconnections of this necklace of different organizations, different professionals, different individuals coming together and building off that energy in such a positive way.

She then commented on how the discussions focused on how to begin capturing the wealth of knowledge that already exists. Yes, there are gaps, she said, but there is an opportunity to build on what is known and the challenge is to find different ways with partners, funders, advocates, and community members to leverage what is known to advance the cause of maternal health equity.

This idea brought her to the issue of positive deviance, of the importance of highlighting the strengths of the Black community, the Indigenous community, and other communities of color and their ability to survive, thrive, and demonstrate the power, the wisdom, and the courage to be able to move forward and push forward.

Her final comment was on the fact that there is an important mirror that is happening at this historical moment.

I think about the image of justice and the scale, and oftentimes her eyes are covered with a cloth. I feel that in this century and at this time that the hiding of her eyes has been removed and there is no doubt in my mind that having the authenticity, the authority from community, and the ability to hold up the mirror to ourselves will be a very important contribution in being able to do the kind of change that we are all striving to achieve.

On that note, Brindis adjourned the workshop.

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## Appendix A

## Workshop Agenda

Advancing Maternal Health Equity and Reducing Maternal Mortality: A Virtual Workshop

> June 7–8, 2021 11:00 am–5:30 pm ET

### **WORKSHOP OBJECTIVES**

To examine the current state of maternal health in the United States and explore the factors needed to enable communities and health care systems to be more effective in reducing maternal morbidity and mortality and improving outcomes for pregnant people through the fourth trimester. The workshop will examine

- the factors shaping maternal health and outcomes, including social determinants, and the role early life events play in shaping health trajectories, and access to and the safety and quality of maternal health care;
- the current state of evidence on maternal health and maternal mortality;
- current promising evidence-informed practices for improving maternal health and reducing maternal mortality from selected states/localities;

- promising models and approaches that apply a life course approach to advance maternal health, including the health of the child through the fourth trimester; and
- research needs across the life course to improve outcomes for mother and child including reproductive and sexual health equity through the fourth trimester.

## MONDAY, June 7

11:00 am-11:10 am

#### Introduction

Clair Brindis, Distinguished Professor of Pediatrics and Health Policy, Division of Adolescent Medicine, Department of Pediatrics and Department of Obstetrics, Gynecology and Reproductive Sciences; Emerita Director, Philip R. Lee Institute for Health Policy Studies, University of California, San Francisco

#### Welcome

Victor Dzau, President, National Academy of Medicine

11:10 am-12:00 pm

## I. Root Cause of Poor Maternal Health Outcomes for Black and Indigenous People

Moderator: Claire Brindis

#### Speakers:

- Joia Crear-Perry, Founder and President, National Birth Equity Collaborative
- Monica McLemore, Associate Professor, Family Health Care Nursing Department, University of California, San Francisco; Affiliated Scientist, Advancing New Standards in Reproductive Health
- Marinah Farrell, Chicanx/Indigenous, Executive Director, Changing Women Iniative

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12:00 pm-1:00 pm

## II. Burden of Maternal Morbidity and Mortality

Moderator: Brownsyne Tucker Edmonds, Assistant Dean for Faculty Affairs, Professional Development, Diversity; Associate Professor of Obstetrics and Gynecology and Clinical Pediatrics, Indiana University School of Medicine

#### Speakers:

- RADM Wanda D. Barfield, Director, Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention
- Laurie Zephyrin, Vice President, Advancing Health Equity, The Commonwealth Fund
- Abigail Echo-Hawk, Pawnee Nation of Oklahoma, Executive Vice President, Seattle Indian Health Board; Director, Urban Indian Health Institute

1:00 pm-2:00 pm

Break

2:00 pm-3:00 pm

#### III. Birthing Experiences in Care Settings

Moderator: Monica McLemore

## Speakers:

- Karen A. Scott, Associate Professor, Ob/Gyn, Reproductive Sciences, Department of Humanities and Social Sciences, University of California, San Francisco, School of Medicine
- Saraswathi Vedam, Professor of Midwifery, Faculty of Medicine, The University of British Columbia; Lead Investigator, Birth Place Lab, MSFHR Health Professional Investigator
- Brownsyne Tucker Edmonds
- Carolyn Sufrin, Assistant Professor of Gynecology and Obstetrics, Associate Director, Center for Medical Humanities and Social Medicine, Johns Hopkins University

3:00 pm-4:00 pm

# IV. Maternal Health and COVID: Exacerbating Vulnerabilities and Use of Technology

Moderator: Melissa Simon, George H. Gardner Professor of Clinical Gynecology, Vice Chair of Research, Department of Obstetrics and Gynecology, Northwestern University Feinberg School of Medicine; Founder and Director, Center for Health Equity Transformation and Chicago Cancer Health Equity Collaborative; Co-Program Leader for Cancer Control and Survivorship, Robert H. Lurie Comprehensive Cancer Center

#### Speakers:

- Stephanie Gaw, Assistant Professor, Maternal-Fetal Medicine, University of California, San Francisco; Co-Principal Investigator, COVID-19 PRIORITY (Pregnancy CoRonavIrus Outcomes RegIsTrY)
- Allison Bryant Mantha, Associate Professor of Obstetrics, Gynecology, and Reproductive Services, Harvard Medical School; Senior Medical Director for Health Equity, Mass General Brigham
- Nia Mitchell, Birth Equity Research Scholar, National Birth Equity Collaborative

4:00 pm-5:30 pm

# V. Maternal Health Issues Related to the Fourth Trimester

Moderator: Melissa Simon

#### Speakers:

- Alison Steube, Professor, Distinguished Scholar, Infant and Young Child Feeding, Department of Maternal and Child Health, Gillings School of Global Public Health; Division Director for Maternal-Fetal Medicine, School of Medicine, University of North Carolina
- Kanika Harris, Director of Maternal Health, Black Women's Health Imperative; Public Health Expert, DC Mayor's Lactation

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Commission; Maternal Health Equity Advisor, State of Maryland

- Karen Tabb Dina, Associate Professor, School of Social Work, University of Illinois at Urbana-Champaign; Faculty Affiliate, Carle Foundation Hospital, Lemann Institute for Brazilian Studies, and Women and Gender in Global Perspectives
- Kay Matthews, Founder, Shades of Blue Project

## **TUESDAY**, June 8

11:00 am

#### Welcome

Brownsyne Tucker Edmonds

11:05 am-12:00 pm

# VI. State Efforts to Redesign Maternal Health Care

Moderator: Brownsyne Tucker Edmonds

#### Speakers:

- Kathryn Menard, Upjohn Distinguished Professor of Maternal-Fetal Medicine, University of North Carolina; Medical Director, North Carolina Pregnancy Medical Home, Community Care of North Caroline
- Chanel Porchia-Albert, Founder and Chief Operating Officer of Ancient Song Doula Services; Commissioner, New York City Commission on Gender Equity
- Zsakeba Henderson, Senior Vice President and Maternal and Child Health Impact Deputy Medical Officer, Office of Maternal and Child Health Impact, March of Dimes

12:00 pm-1:00 pm

## VII. Implementation of Statewide Policies and Mandates to Advance Maternal Health Equity

Moderator: Claire Brindis

#### Speakers:

 Ann E. B. Borders, Executive Director and Obstetric Lead, Illinois Perinatal Quality Collaborative: Maternal Fetal Medicine Physician, NorthShore University HealthSystem; Clinical Associate Professor, Pritzker School of Medicine, University of Chicago

- Charlene Collier, Medical Director, Bureau of Maternal and Infant Health, Mississippi State Department of Health in Jackson, Mississippi; Director and Co-Founder, Mississippi Perinatal Quality Objective
- Nourbese Flint, Policy Director, Black Women for Wellness; Executive Director, Black Women for Wellness Action Project

1:00 pm-2:00 pm

**Break** 

2:00 pm-3:00 pm

## VIII. Promising Strategies Using a Reproductive Well-Being Approach to Advance Maternal Health

Moderator: Monica McLemore

## Speakers:

- Aza Nedhari, Executive Director, Mamatoto Village
- Ebony Marcelle, Director of Midwifery, Community of Hope Family Health and Birth Center
- Camie Jae Goldhammer, Sisseton-Wahpeton, Found and Chair, Native American Breastfeeding Coalition of Washington; Founding Mother and President Elect, National Association of Professional and Peer Lactation Supporters of Color
- Grace Lubwama, Chief Executive Officer, YWCA Kalamazoo (via video)

3:00 pm-4:00 pm

## IX. Federal Policy Approaches to Address Maternal Health and Maternal Morbidity

Moderator: Kosali Simon, Herman B. Wells Endowed Professor, O'Neill School of Public and Environmental Affairs, and Associate Vice Provost for Health Sciences, Indiana University APPENDIX A 173

#### Speakers:

- Jamila Taylor, Director of Health Care Reform and Senior Fellow, The Century Foundation
- Jennifer Moore, Founding Executive Director, Institute for Medicaid Innovation
- Dawn Godbolt, Policy Director, National Birth Equity Collaborative

4:00 pm-5:30 pm

X. Research and Funding Needs to Increase Knowledge Generation and Improve Maternal Health Outcomes

Moderator: Claire Brindis

#### Speakers:

- Juanita J. Chinn, Sociologist and Demographer, Population Dynamics Branch, National Institute of Child Health and Human Development
- Kathryn Schubert, President and Chief Executive Officer, Society for Women's Health Research
- Monique Shaw, Program Officer, Robert Wood Johnson Foundation
- Tenesha Duncan, Principal, Birth Equity, Tara Health Foundation

5:30 pm

**Workshop Adjourns** 



## Appendix B

## Biographical Sketches of Workshop Speakers, Moderators, and Planning Committee Members

Wanda D. Barfield, M.D., M.P.H., FAAP, Rear Admiral (retired), is the director of the Division of Reproductive Health (DRH) within the National Center for Chronic Disease Prevention and Health Promotion at the Centers for Disease Control and Prevention (CDC). She is a retired assistant surgeon general in the U.S. Public Health Service. Dr. Barfield joined CDC in 2000 as part of its Epidemic Intelligence Service, where she worked in neonatal and perinatal health. She was named the division director in 2010. Dr. Barfield's research focuses on maternal/infant morbidity and mortality; early child health services utilization; improving access to risk-appropriate perinatal care; and advancing the quality of maternal, infant, and reproductive health data for public health action. She has published more than 120 scientific articles in these areas. As the DRH director, Dr. Barfield has led efforts to provide optimal and equitable health to women, infants, and families through improved surveillance and applied public health research during the critical junctures of population health: pregnancy, infancy, and adolescence. She has built and strengthened numerous strategic partnerships with multiple maternal and child health organizations. In addition, Dr. Barfield is an associate professor of pediatrics with the Uniformed Services University of the Health Sciences and an adjunct professor at the Emory University School of Medicine. She is a fellow with the American Academy of Pediatrics (AAP) and is the CDC liaison to the AAP Section on Neonatal-Perinatal Medicine and the Committee on Fetus and Newborn. She continues to do clinical work in neonatology, providing care to premature and other critically ill newborns.

Ann E. B. Borders, M.D., M.Sc., M.P.H., is the executive director and the obstetric lead at the Illinois Perinatal Quality Collaborative, a collaborative of more than 100 birthing hospitals focused on improving outcomes for mothers and newborns. She is a maternal-fetal medicine physician with the NorthShore University Health System Department of Obstetrics and Gynecology and is a clinical associate professor of obstetrics and gynecology at the University of Chicago Pritzker School of Medicine. Dr. Borders received an M.Sc. in health policy from the London School of Hygiene & Tropical Medicine, and an M.D. from Harvard Medical School in 1999. She completed a maternalfetal medicine fellowship and a National Research Service Award postdoctoral fellowship in health services research at Northwestern University in 2006. In 2007, she completed an M.P.H. at Northwestern University. Dr. Borders serves on the National Network of Perinatal Quality Collaboratives Executive Committee and is a member of the Illinois Maternal Mortality Review Committee. She is a National Institutes of Health-funded researcher focused on addressing disparities in pregnancy outcomes for vulnerable populations.

Claire Brindis, Dr.P.H., M.P.H. (Planning Committee and Moderator), is a Distinguished Emerita Professor of Pediatrics and Health Policy in the Division of Adolescent Medicine in the Department of Pediatrics and the Department of Obstetrics, Gynecology and Reproductive Sciences and an emerita director of the Philip R. Lee Institute for Health Policy Studies at the University of California, San Francisco (UCSF). She is also the co-director of the Adolescent and Young Adult Health National Resource Center and the founding director of the Bixby Center for Global Reproductive Health at UCSF. Dr. Brindis, a native of Argentina and the first to attend college in her family, conducts research focused on child, adolescent, and women's health policy and on the implementation of health care reform and immigration health. Incorporating a variety of quantitative and qualitative methodologies centered on community participatory research, her research focuses on program evaluation and the translation of research into policy at the local, state, and national levels. Dr. Brindis's policy research focuses on how racial and other social determinants and disparities impact health outcomes, including access to quality care and health insurance coverage. Her research interests also include consumer engagement in health care system redesign; tracking the implementation of the Patient Protection and Affordable Care Act on adolescents, young adults, and women, including barriers encountered in enrolling these and other marginalized populations; the evaluation of the UCSF Preterm Initiative; and research on the health and mental health needs of Dreamers (Deferred Action for Childhood Arrivals or DACA). Her writings include Policy and Advocacy Evaluation: Theory and Practice (Stanford Press). Throughout these and other projects, Dr. Brindis is committed to closing the gap between evidence-based

innovation and its application to policy and programs, as well as mentoring of the next generation of pioneers. Dr. Brindis received her Dr.P.H. in public health and behavioral sciences from the University of California, Berkeley.

Juanita J. Chinn, Ph.D., M.A., is a sociologist and a demographer in the Population Dynamics Branch at the National Institute of Child Health and Human Development (NICHD), where she directs the Demography of Health, Demography of Health Disparities, Human Morbidity and Mortality, and Population Composition programs. Dr. Chinn co-chairs the NICHD Maternal Health Coordinating Committee and serves on the trans-National Institutes of Health (NIH) UNITE initiative to identify and address structural racism. Before joining NICHD in January 2017, she was the Department of Health and Human Services' Office of Minority Health's Health Disparities Fellow at the National Center for Health Statistics, where she led efforts in stimulating health disparities research and programs. Her areas of expertise include racial, ethnic, and nativity disparities in health, morbidity, and mortality; infant and maternal health; women's health; data policy; social demography; acculturation and assimilation; and the social determinants of health. Dr. Chinn earned her M.A. and Ph.D. in sociology, with a specialization in demography, from The University of Texas at Austin. She trained as an NIH postdoctoral fellow in the Office of Population Research at Princeton University. She holds an Sc.B. in applied mathematics and psychology from Brown University.

Charlene Collier, M.D., M.P.H., M.H.S., is the medical director of the Bureau of Maternal and Infant Health at the Mississippi State Department of Health in Jackson, Mississippi. She is also the director and the co-founder of the Mississippi Perinatal Quality Collaborative and chairs the Maternal Mortality Review Committee. Dr. Collier practices obstetrics and gynecology at the University of Mississippi Medical Center. In addition to her duties as an associate professor, she co-chairs the Ob/Gyn Department's Diversity, Equity, and Inclusion Task Force. She is a member of the American College of Obstetricians and Gynecologists' Committee on Obstetrics Practice as well as the Executive Committee of the National Network of Perinatal Quality Collaboratives.

**Joia Crear-Perry, M.D., FACOG,** is a physician, policy expert, thought leader, and advocate for transformational justice. As the founder and the president of the National Birth Equity Collaborative (NBEC), she identifies and challenges racism as a root cause of health inequities. She is a highly sought after trainer and speaker who has been featured in national and international publications, including Essence and Ms. Magazine. In 2020, Dr. Crear-Perry

was honored by *USA Today* in its "Women of the Century" series and featured on ABC *Nightline's* "Hear Her Voice." Dr. Crear-Perry has twice addressed the United Nations Office of the High Commissioner for Human Rights to elevate the cause of gender diversity and urge a human rights framework toward addressing maternal mortality. Previously, she served as the executive director of the Birthing Project, the director of Women's and Children's Services at the Jefferson Community Healthcare Center, and as the director of clinical services for the City of New Orleans Health Department.

Tenesha Duncan, M.A., leads Tara Health Foundation's strategy and investments in birth equity, where she focuses on the intersection of birth and economic justice to elevate community-led solutions that improve care quality and outcomes. Prior to joining Tara Health, Ms. Duncan was an investment associate at Rhia Ventures, where she supported deal evaluation and managed reproductive health care service delivery projects. She has led and facilitated coalitions of abortion providers and advocates and also served as the membership director of the National Abortion Federation, where she focused on quality in abortion care delivery and experience, organizational development, and clinic sustainability. She also previously worked as the administrator/director of Southwestern Women's Surgery Center, where she led operations and business development. Ms. Duncan is an M.B.A. candidate at Howard University, holds a master's degree in psychology from Kingston University, and earned her bachelor's degree in psychology from the University of Oklahoma.

Abigail Echo-Hawk, M.A., is an enrolled member of the Pawnee Nation of Oklahoma. She is currently the executive vice president at the Seattle Indian Health Board and the director of the Urban Indian Health Institute. Currently, Ms. Echo-Hawk is part of multiple committees, boards, and work groups, including the Best Starts for Kids Board, the March of Dimes Health Equity Workgroup, the Tribal Collaboration Working Group with the National Institutes of Health All of Us Research Program, the Advisory Committee for Health Equity Research at the Robert Wood Johnson Foundation, the National Institute on Drug Abuse American Indian and Alaska Native Collaborative Research Engagement Workgroup, and the Board of Data for Indigenous Justice. In the past, Ms. Echo-Hawk spent 8 years as the tribal liaison with Partnerships for Native Health at the University of Washington School of Public Health. In 2016, she became the co-director of Partnerships of Native Health at the Washington State University Institute for Research and Education to Advance Community Health. She was also the tribal relationship facilitator at the Institute of Translational Health Sciences at the University of Washington from 2010 to 2015. In 2015, she became a board member for the Center for Indigenous Law and Justice. Ms. Echo-Hawk has a B.A. in

interdisciplinary studies and an M.A. in policy studies, both from the University of Washington. She is an expert in American Indian and Alaska Native health, including strengths and resiliencies as well as deficits and disparities.

Marinah V. Farrell, Midwife, LM, CPM, is the executive director of the Changing Women Initiative. She identifies as a first-generation, two-spirit Chicanx/Indigenous daughter of a medicine woman from Chihuahua, Mexico, and mother to mixed-race children from Mexican, Pascua Yaqui, and Irish/ English descent. Ms. Farrell is active in multiple public health initiatives and coalitions within her community and at the national and international levels. Her background includes diverse activism, such as street-level medic work and immigration activism in Arizona, clinical/government policy work in Mexico and Africa, organizational development and facilitation in the United States and Mexico with various nonprofits, and as a founding board member of a primary care free clinic, Phoenix Allies for Community Health. Ms. Farrell is passionate about advocating for traditional and community health workers and has worked as a staff midwife for birth centers and medical facilities internationally, as a program coordinator for traditional midwives, and as an educator. Ms. Farrell is the owner of Phoenix Midwife, a long-standing midwifery practice, and Casa Ancestral, focused on creating a traditional healing space. She also served as the past president for the Midwives Alliance of North America. Other current roles include board member for the National Latina Institute for Reproductive Justice and the founder of Parteras de Maiz, an umbrella organization dedicated to advocacy for traditional birth work and health justice that includes projects such as the Dignity Birth Campaign and the Good Birth for All network and podcast.

Nourbese Flint, M.A., serves as the policy director at Black Women for Wellness (BWW) and is the executive director of the Black Women for Wellness Action Project. Here she uses her skill set in policy and civic engagement and her background in health to decrease systemic and institutional barriers that exasperate health disparities seen in women of color. Before joining BWW, Ms. Flint studied women's health in both Spain and Cuba and journalism in Scotland. Ms. Flint's communication background includes serving as the communication director for the Center of Women's Health and Human Rights, as well as reporting for KPFK evening news. In addition, she has an M.A. in women's health from Suffolk University, where she specialized in health disparities as it relates to media influence. She is a founding member of Trust Black Women, a national coalition dedicated to increasing respect and support of Black women, and she was the co-chair of girls policy for the California Women's Agenda, an organization that intersects international issues of women and girls and the United States with the mission to ratify

the Convention on the Elimination of All Forms of Discrimination against Women. Currently, Ms. Flint is one of only a handful of Black women working on assisted reproductive technologies, biotechnologies, and their intersection with reproductive justice and cultural ethics.

Elena Fuentes-Afflick, M.D. (Planning Committee), is a professor and the vice chair of pediatrics, the chief of pediatrics at the Zuckerberg San Francisco General Hospital, and the vice dean for academic affairs in the School of Medicine at University of California, San Francisco (UCSF). In 2012, Dr. Fuentes-Afflick was appointed the vice dean for academic affairs and faculty development for the School of Medicine. She is responsible for overseeing all academic affairs in the School of Medicine, including the recruitment, development, and advancement of a diversified academic workforce of the highest caliber. She is also responsible for overseeing innovative programs for faculty orientation, career development, and leadership training. After completing her undergraduate and medical education at the University of Michigan, Dr. Fuentes-Afflick came to UCSF for her residency training in pediatrics, followed by a fellowship in health policy at UCSF and an M.P.H. in epidemiology from the University of California, Berkeley. She has served in several important national leadership roles, including as the president of the Society for Pediatric Research, the president of the American Pediatric Society, and service on the Council of the National Institute for Child Health and Development. Dr. Fuentes-Afflick was chair of the UCSF Academic Senate from 2009 to 2011. She was elected to the National Academy of Medicine in 2010 and has served as a member of several consensus study report committees.

Stephanie Gaw, Ph.D., M.D., is an assistant professor in the Division of Maternal-Fetal Medicine in the Department of Obstetrics, Gynecology and Reproductive Sciences at the University of California, San Francisco (UCSF). She completed her M.D. and Ph.D. in microbiology and immunology at the Albert Einstein College of Medicine in New York through the Medical Scientist Training Program. She completed her residency training in OB/GYN at UCSF and a fellowship in maternal-fetal medicine at the University of California, Los Angeles. She has a long-standing interest in global infectious disease and maternal-child health, which started from her service as a Peace Corps volunteer in rural Honduras and has led to her current research in perinatal infections. Her laboratory group conducts translational research on placental infections, including malaria in pregnancy, Zika virus, and more recently, SARS-CoV-2 infection in pregnancy and lactation. She has global collaborations with researchers in Brazil, Kenya, and Uganda. She is co-principal investigator of PRIORITY (Pregnancy CoRonavIrus Outcomes RegIsTrY), a nationwide study of pregnant or recently pregnant people who are either under

investigation for COVID-19 or have been confirmed to have COVID-19. She has recently served as a temporary advisor to the World Health Organization on mother-to-child transmission of SARS-CoV-2. Her research has been funded by the National Institutes of Health, the Reproductive Scientist Development Program, the Foundation for SMFM, the CDC Foundation, the Bill and Melinda Gates Foundation, the California Health Care Foundation, the Robert Wood Johnson Foundation, and the Yellow Chair Foundation.

**Dawn Godbolt, Ph.D.,** is the policy director at the National Birth Equity Collaborative (NBEC), where she works to improve maternal health disparities by creating a more equitable health care system through federal policy levers. She sits on the National Quality Forum's Maternal Mortality and Morbidity Committee and chairs the Equitable Maternal Health Coalition policy working group. Prior to joining NBEC, she was at the National Partnership for Women & Families, where she worked to integrate a reproductive justice framework into the maternal health portfolio as the senior manager for maternal health initiatives. Dr. Godbolt completed her doctorate in sociology from Florida State University and a fellowship with the OpEd Project, where she was trained to influence thought leadership. Her previous work examined race differences in mothers' fear of allowing children outside, disparities in neighborhood factors, and the connection among stereotypes, religion, and obesity.

Camie Jae Goldhammer (Sisseton-Wahpeton), M.S.W., LICSW, IBCLC, is a clinical social worker and a lactation consultant. Ms. Goldhammer is the founder and the chair of the Native American Breastfeeding Coalition of Washington. She is also a founding mother and the president-elect of the National Association of Professional and Peer Lactation Supporters of Color. In 2013 she became Washington State's first Native American International Board-Certified Lactation Consultant®. She is a member of the Center for Social Inclusion's First Food Racial Equity Cohort. She worked as a campaign director with MomsRising, working to bring paid family and medical leave to Washington State, which was signed into law in July 2017. In fall 2017, Ms. Goldhammer launched the Indigenous Breastfeeding Counselor Certification, which is a 45-hour foundational lactation counselor program for those that identify as Native/Indigenous/First Nations. In November 2018, she and Kimberly Moore-Salas (Diné) were the first Native Americans to be elected to the United States Breastfeeding Committee Board of Directors. Both were reelected for a second term in fall 2020. In April 2021, she left her role as the program manager for United Indians of All Tribes' Daybreak Star Doulas (which she also developed) and Our Strong Fathers and is in the early stages of starting a new nonprofit called Hummingbird Indigenous Family Services, whose first program is Hummingbird Indigenous Doulas. She is a national leader on topics of racial equity and first food justice.

Kanika Harris, Ph.D., M.P.H., currently works as the director of maternal health for the Black Women's Health Imperative. She is a behavioral health scientist, with a special focus on health equity, maternal health, and women's health. She is a mother of three, doula, and birth justice advocate. She also serves as the maternal health equity advisor for the state of Maryland and the public health expert for the lactation commission in Washington, DC. She received her M.P.H. in international development from the Morehouse School of Medicine and her Ph.D. in health behavior and health education from the University of Michigan.

Zsakeba Henderson, M.D., currently leads the Office of Maternal and Child Health Impact at March of Dimes, providing strategic direction and clinical expertise across the organization to help end the maternal and infant health crisis. She is a board-certified obstetrician-gynecologist, and previously led the program in support of state-based Perinatal Quality Collaboratives at the Centers for Disease Control and Prevention's (CDC's) Division of Reproductive Health, including leading the establishment of the National Network of Perinatal Quality Collaboratives (NNPQC). Dr. Henderson currently serves as an executive committee member and the obstetric co-chair for the NNPOC. She received her B.S. in biochemistry from Oakwood University in Huntsville, Alabama, and her M.D. from Harvard Medical School in Boston, Massachusetts. She also completed her internship and residency at Harvard at the Brigham and Women's Hospital/Massachusetts General Hospital Integrated Residency Program in Obstetrics and Gynecology. She subsequently entered the Epidemic Intelligence Service at CDC in the Division of STD Prevention. Dr. Henderson is a nationally recognized leader in the growth and spread of perinatal quality improvement efforts across the country, working toward the goal of making the United States a safer place to give birth and be born.

Grace Lubwama, Ph.D., M.P.H., is the chief executive officer of the YWCA in Kalamazoo, the first and oldest YWCA in the state of Michigan, dedicated to eliminating racism; empowering women; and promoting peace, justice, freedom, and dignity for all. YWCA Kalamazoo is leading the charge around public health issues such as domestic violence (as the only domestic violence shelter in Kalamazoo County) and sexual assault (as the only sexual assault nursing examination program in Kalamazoo County) and is the founding organization of the Cradle Kalamazoo, an infant mortality initiative in Kalamazoo. Dr. Lubwama received her B.A. in fine arts and industrial design from Makerere University in Kampala, Uganda, her M.P.H. from Boston University in Boston, Massachusetts, and her Ph.D. in policy, planning, and development from the University of Southern California.

Allison Bryant Mantha, M.D., M.P.H., is an associate professor of obstetrics, gynecology, and reproductive sciences at Harvard Medical School. She received degrees in biology, public health, and medicine from Harvard University, where she also completed training in obstetrics and gynecology. She has had fellowships in maternal/fetal medicine and The Commonwealth Fund/ Harvard University Fellowship in Minority Health Policy. She is the senior medical director for health equity at the Mass General Brigham integrated health system. She served as the vice chair for quality, equity, and safety in the Department of Obstetrics and Gynecology at Mass General Hospital, a role she designed to underscore the critical role of equity in care quality for all patients. She currently serves as a member of several regional and national women's health and equity improvement efforts, among them, the Massachusetts Department of Public Health's Maternal Mortality Review Committee, which she chairs, American College of Obstetricians and Gynecologists' Committee on Obstetric Practice, and the board of directors of the Society for Maternal-Fetal Medicine.

Ebony Marcelle, CNM, M.S., FACNM, is the director of midwifery at Community of Hope Family Health and Birth Center. Formerly the administrative chief of midwifery service at Medstar Washington Hospital Center, she completed her nursing education at Georgetown University and midwifery at Philadelphia University. Save the Child recognized her as its "Real Award Midwife Honoree" in 2014. In 2015 she was recognized by the American College of Nurse Midwives with the "Young Whippersnapper" award for midwives excelling professionally with less than 10 years of experience. In 2018 she completed the Duke University and Johnson & Johnson nursing leadership fellowship. In 2021 she will complete The Equity Lab's "Seeding Disruption" fellowship. Ms. Marcelle is known for her passion in midwifery and midwifery's role in social justice. She continues to build culturally aware midwifery with driven clinical models of care, specifically for underserved Black women. She is currently serving on the boards of March for Moms, the National Association for the Advancement of Black Birth, and the American Association of Birth Centers. She is also adjunct faculty at Georgetown University.

Kay Matthews is the founder of the Shades of Blue Project. She graduated with a 2-year degree in early childhood development from North Harris College in Houston, Texas, and furthered her education in the mental health field by becoming a licensed community health worker. She has also received numerous awards from both her community and peers and sits on the boards and is partner with several national organizations, along with writing her first best-seller, a self-help journal titled 365 Days to Recovery: Finding Your Way Out of the Darkness and Recovery State of Mind: Inspired You Daily Journal. Ms.

ADVANCING MATERNAL HEALTH EQUITY

Matthews is actively teaching and speaking to women of all ages to help them better understand how important it is to advocate for themselves before, during, and after childbirth. She helps them realize that they have the ability to have a successful birth outcome and she ensures that they know of resources available with respect to maternal mental health. To Ms. Matthews, this is the most important aspect of the work she does within the community and it is the motivation that she uses to continue to educate communities worldwide.

Monica R. McLemore, Ph.D., M.P.H., RN (Moderator), is a tenured associate professor in the Family Health Care Nursing Department at the University of California, San Francisco; an affiliated scientist with Advancing New Standards in Reproductive Health; and a member of the Bixby Center for Global Reproductive Health. She retired from clinical practice as a public health and staff nurse after a 28-year clinical nursing career. Her program of research is focused on understanding reproductive health and justice. To date, she has 69 peer-reviewed articles, op-eds, and commentaries. Her research has been cited in The Huffington Post, Lavender Health, three amicus briefs to the Supreme Court of the United States, and two National Academies of Sciences, Engineering, and Medicine publications, and in a data visualization project titled "How to Fix Maternal Mortality: The First Step Is to Stop Blaming Women," which was published in the 2019 "Future of Medicine" edition of Scientific American. Her work has appeared in publications such as Dame Magazine, Politico, and ProPublica/NPR, and she made a voice appearance in Terrance Nance's HBO series Random Acts of Flyness. She is the recipient of numerous awards and currently serves as the chair-elect for the Sexual and Reproductive Health section of the American Public Health Association. She was inducted as a fellow of the American Academy of Nursing in 2019.

M. Kathryn Menard, M.D., M.P.H., is a distinguished professor of obstetrics and gynecology in the Division of Maternal-Fetal Medicine at the University of North Carolina (UNC) School of Medicine, where she served for 14 years as the director of the Division of Maternal-Fetal Medicine and the director of the Center for Maternal and Infant Health. In addition to her duties at UNC, she serves as the medical director of North Carolina's Pregnancy Medical Home through Community Care of North Carolina, a statewide program that supports Medicaid beneficiaries and their care providers in access to high-quality maternity care. She also serves on North Carolina's Maternal Mortality Review Committee and the Maternal Health Task Force. Throughout her career in academic medicine, Dr. Menard has worked to highlight the shared goals of clinical medicine and public health, thus bringing diverse perspectives together, promoting collaboration, and realizing synergy. She has worked to elevate attention to maternal health needs by advancing two

important initiatives: (1) strengthening regional systems by defining Levels of Maternal Care, and (2) providing foundational leadership for the broad dissemination and implementation of maternal safety bundles through the Health Resources and Services Administration (HRSA)-funded Alliance for Innovation on Maternal Health. Her current work includes engagement with the HRSA-sponsored Maternal Health Learning and Innovations Center based at the UNC Gillings School of Global Public Health. Dr. Menard completed her residency in obstetrics and gynecology at the University of Pennsylvania. Her maternal-fetal medicine fellowship training was at UNC as a Robert Wood Johnson Clinical Scholar.

Nia Mitchell, M.P.H., is a birth equity research scholar with the National Birth Equity Collaborative. As an evaluator and a researcher, she is committed to centering Black women and birthing people's lived experiences, models of care, scholarship, and activism in her work. Ms. Mitchell received a B.A. in anthropology from Georgia State University, an M.P.H. from the Morehouse School of Medicine, and is currently pursuing her Ph.D. in qualitative research and evaluation methodologies from the University of Georgia. Throughout her career, she has implemented and evaluated the effectiveness of education, health, and civic engagement programs serving diverse families and communities (e.g., immigrants and refugees, women, queer and trans youth of color, low income).

Jennifer E. Moore, Ph.D., RN, FAAN, is the founding executive director at the Institute for Medicaid Innovation (IMI). She is an internationally recognized leader in Medicaid and maternal and child health. With more than 20 years of experience, her work, at the intersection of clinical practice, research, and policy, positions her as a thought leader and a passionate advocate for vulnerable populations. This multifaceted emphasis makes her a respected participant in the national dialogue on these and other health care topics. As the founding executive director of IMI and an assistant research professor at the University of Michigan Medical School's Department of Obstetrics and Gynecology, Dr. Moore focuses her efforts on strategically bringing together payers, clinicians, researchers, and government to design and evaluate innovative approaches to address maternal health issues such as opioid use during pregnancy, value-based purchasing, disparities, social determinants of health, and maternal mortality and morbidity. Dr. Moore's current grant-funded research projects include work with the Robert Wood Johnson Foundation to assess Medicaid access and coverage for the nation's most vulnerable through the first national longitudinal survey of Medicaid-managed care organizations in seven key categories, including value-based purchasing, high-risk care coordination, women's health, pharmacy, child and adolescent health, long-term services and supports, behavioral health, and social determinants of health. She also is involved in projects focused on reducing disparities through payment and delivery system reform, an exploration into innovative mental health services for pregnant women under Medicaid managed care, and models of care to improve maternal health care delivery and patient outcomes in Medicaid. Many honors and awards have been conferred on Dr. Moore, including the Carole Weisman and Gary Chase Gender-Based Research of the Year Award, presented in 2017 by AcademyHealth. During her 3 years at the Agency for Healthcare Research and Quality, she was honored with the Director's Award of Merit four times. Dr. Moore holds a Ph.D. and master's degree in health systems and policy from the University of Michigan, as well as a B.S.N.

Aza Nedhari, LM, CPM, M.S., has more than 18 years of experience in community organizing, reproductive justice, and program development. She is a licensed certified professional midwife, a family counselor, and the founding executive director of Mamatoto Village. Ms. Nedhari is a fiercely dedicated woman who believes that by promoting a framework of justice, the barriers in maternal and child health begin to dissipate, giving rise to healthy individuals, healthy families, and healthy communities. She is pursuing her doctorate in human services with a concentration in organizational leadership and management, with an eye toward the sustainability of people of color–led organizations and the cultivation of innovative models of perinatal care delivery in high-needs communities.

Chanel L. Porchia-Albert, CD, is the founder and the chief operating officer of Ancient Song Doula Services, a reproductive health organization of more than 70 full-spectrum, community-based doulas focused on providing resources and full-spectrum doula services to women of color and marginalized communities throughout New York City (NYC) and northern New Jersey. Her work within infant and maternal health has led her across the globe to Uganda, where she has served as a maternal health strategist in rural war-torn areas to address the lack of resources to birthing mothers. She is a certified lactation counselor, midwifery assistant, and vegan chef who has served on various advisory boards throughout the country. Her work in birth and reproductive justice continues to span into the research and methods of care of marginalized people and people of color, bringing a human rights framework into birthing rooms and beyond into institutional reform and accountability measures within health care to address implicit bias and racism. When she is not working on legislative policy or facilitating workshops, you can find her spending time with her six children. To name a few of her achievements, she has served as a consultant for the Association of Maternal & Child Health Programs and the NYC Department of Health and Mental

Hygiene, as well as assisting in the creation of the Respectful Care at the Birth document that has been in widespread use at health care institutions, engaging providers in birth justice. Most recently, she was appointed by NYC Mayor DeBlasio as a commissioner to the NYC Commission on Gender Equity and is an advisory board member for the Marymount College School of Politics & Human Rights. She has served on the advisory board at Ariadne Labs at Harvard Medical School, on the board of directors for March for Moms, and as a board member of the Foundation for the Advancement of Midwifery and Village Birth International. Her and Ancient Song's work has been featured on CNN's Champions for Change and the cover of *Working Mother* Magazine and in *The New York Times, Self* magazine, and more.

Kathryn Schubert, M.P.P., is the president and chief executive officer of the Society for Women's Health Research (SWHR), where she leads the organization's efforts to promote research on sex as a biological variable and to improve women's health through science, policy, and education. Prior to joining SWHR in April 2020, Ms. Schubert served as the chief advocacy officer at the Society for Maternal-Fetal Medicine (SMFM), where she oversaw the organization's advocacy and communications activities. Prior to joining SMFM, she was a senior vice president at CRD Associates, where she represented patient advocacy organizations, physician organizations, and coalitions. Ms. Schubert previously served in key staff roles for U.S. Representatives Nancy Johnson (R-CT) and Wayne Gilchrest (R-MD), and brings a unique perspective of working across party lines to achieve policy goals. She currently serves as the chair of the board of the Maternal Mental Health Leadership Alliance and as an advisor to the John E. Lewy Fund for Children's Health. She is a past president of Women in Government Relations and has an M.P.P. with a concentration in health policy from The George Washington University. She attended Mary Washington College in Fredericksburg, Virginia, where she earned a B.A. in political science.

Karen A. Scott, M.D., M.P.H., FACOG, is an associate professor in the Department of Obstetrics, Gynecology, and Reproductive Sciences with a joint appointment in the Department of Humanities and Social Sciences at the University of California, San Francisco, School of Medicine. She is a social improvement and implementation scientist and activist grounded in a Black feminist—reproductive justice praxis with formal training and experience as a community-based OB/GYN and applied epidemiologist. Dr. Scott's ethical, theoretical, and methodological approaches interrogate health services provision, evaluation, and training in antepartum, intrapartum, and postpartum units as sites through which racism (structural, gendered, and obstetric) is enacted and imposed on the humanity, bodies, and lives of Black women,

mothers, and people in the afterlife of slavery. She is also the developer and the owner of the first and only validated Patient-Reported Experience Measure of OBstetric racism®, known as the PREM-OB Scale™ (pronounced Oh-Bee), and she is the principal investigator with the SACRED Birth study. Dr. Scott also developed the Virtual Perinatal Quality Improvement Prioritization by Affected Communities (V-QPAC) Protocol, a Black feminist ethnographic methodology to facilitate community participation in prioritizing untested sociocultural perinatal quality improvement recommendations across the domains in the PREM-OB Scale™ in order to mitigate obstetric racism during hospital-based labor, birth, and postpartum experiences.

Monique Shaw, Ph.D., M.P.H., is a program officer at the Robert Wood Johnson Foundation. A committed public health practitioner, she draws on her prior work in health education, health policy research, program coordination, and community outreach to help align systems and build a culture of health that provides everyone in America a fair and just opportunity for health and well-being. She views her work as enabling health care, public health, and social service systems to work closely together to meet the goals and needs of the people they serve. She strives to use health policy change as a vehicle to promote cross-sector collaboration in addressing social determinants of health and to advance health equity. Previously, Dr. Shaw served as the program coordinator for the University of Pennsylvania's M.P.H. program and the assistant program director at the University of the Sciences. Earlier, Dr. Shaw was the outreach projects manager for Philadelphia Coordinated Health Care, the southeastern Pennsylvania health care quality unit. There she helped increase access to community physical and mental health care for people with intellectual and developmental disabilities. Dr. Shaw earned her doctorate in health policy from the University of the Sciences in Philadelphia, M.P.H. from Drexel University with a focus on community health and prevention, and B.S. in psychology from Howard University. Dr. Shaw is a practicing full-spectrum doula supporting and advocating for women of color throughout their reproductive health journeys.

**Kosali Simon, Ph.D., M.P.H.** (*Moderator*), is the Herman B. Wells Endowed Professor and the associate vice provost for health sciences at Indiana University, where she is faculty in the O'Neill School of Public and Environmental Affairs. She is the editor of the *Journal of Health Economics* and the co-editor at *Journal of Human Resources*. Dr. Simon is a nationally known health economist who specializes in applying economic analysis in the context of health insurance and health policy. Her current research focuses on the impact of health insurance reform on health care and labor market outcomes, the causes and consequences of the opioid crisis, and COVID-19-related policy. She is also

active in national leadership roles in her profession, serving on several boards. She serves as the vice president of the governing body of the Association for Public Policy Analysis and Management.

**Melissa Simon, M.D., M.P.H.** (*Planning Committee* and *Moderator*), is the George H. Gardner Professor of Clinical Gynecology and the vice chair of research in the Department of Obstetrics and Gynecology at the Northwestern University Feinberg School of Medicine. She is also the founder and the director of the Center for Health Equity Transformation and the Chicago Cancer Health Equity Collaborative and the co-program leader for cancer control and survivorship for the Robert H. Lurie Comprehensive Cancer Center. She is an expert in implementation science, women's health across the lifespan, minority health, community engagement, and health equity. She has been recognized with numerous awards for her substantial contribution to excellence in health equity scholarship, women's health and mentorship, including the Presidential Award in Excellence in Science Mathematics and Engineering Mentorship and as a Presidential Leadership Scholar. She is a former member and the current consultant to the United States Preventive Services Task Force and serves on the National Institutes of Health's Office of Research in Women's Health Advisory Committee. She is also a member of the National Academies of Sciences, Engineering, and Medicine's Roundtable on the Promotion of Health Equity and the National Academy of Medicine's Leadership Consortium's Culture Inclusion and Equity Collaborative. She completed her bachelor's degree at the University of Chicago, her M.D. at Rush Medical College, her residency at Yale University, and her fellowship in family planning at Northwestern University.

Alison Stuebe, M.D., M.Sc., FACOG, FABM, completed her obstetrics and gynecology residency at Brigham and Women's Hospital and Massachusetts General Hospital in Boston. She completed fellowship training in maternal-fetal medicine at Brigham and Women's and she earned a masters in epidemiology from the Harvard T.H. Chan School of Public Health. She has published more than 170 peer-reviewed articles. She is currently a division director for maternal-fetal medicine at the University of North Carolina (UNC) School of Medicine and the Distinguished Professor of Infant and Young Child Feeding at the UNC Gillings School of Global Public Health. She has been awarded grant funding from the National Institutes of Health, the Agency for Healthcare Research and Quality, and the Patient-Centered Outcomes Research Institute. Her current research focuses on developing models for holistic and equitable care of families during the fourth trimester. She is a member of the Steering Committee for Moms Rising, North Carolina, and she is actively engaged in professional organizations. She is the president

of the Academy of Breastfeeding Medicine and a former board member of the Society for Maternal-Fetal Medicine. At the American College of Obstetricians and Gynecologists she is a member of both the Breastfeeding Expert Work Group and the Maternal Mental Health Expert Work Group, and she chaired the Task Force on Reinventing Postpartum Care.

Carolyn Sufrin, M.D., Ph.D., M.A., is a medical anthropologist and an obstetrician-gynecologist specializing in family planning at Johns Hopkins University. She is an assistant professor in the Department of Gyn/Ob and the associate director of the Center for Medical Humanities and Social Medicine at the School of Medicine and in Health, Behavior and Society at the Johns Hopkins Bloomberg School of Public Health. Dr. Sufrin has worked extensively on reproductive health issues affecting incarcerated women, from providing clinical care in jail to research, policy, and advocacy. Her work is situated at the intersection of reproductive justice, health care, and mass incarceration, which she examines in her book, Jailcare: Finding the Safety Net for Women Behind Bars. She is the founder and the director of the Johns Hopkins-based research group Advocacy and Research on Reproductive Wellness in Incarcerated People program, which conducts National Institutes of Health- and foundation-funded research on issues such as pregnancy outcomes in prisons and jails, medication-assisted treatment for pregnant people in jails, and contraception access in carceral settings. Dr. Sufrin serves on the board of the National Commission on Correctional Health Care as the liaison for the American College of Obstetricians and Gynecologists.

Karen Tabb Dina, Ph.D., M.S.W., is an associate professor in the University of Illinois at Urbana-Champaign School of Social Work and a faculty affiliate at Carle Foundation Hospital, the Lemann Institute for Brazilian Studies, and Women and Gender in Global Perspectives. Her research agenda focuses on identifying mental health risk factors for morbidity and mortality among perinatal women and clinical factors to improve minority health. She is an expert collaborator (in the areas of mental health, maternal health, and North America) for the Global Burden of Disease Study, where she contributes in estimating population morbidity and mortality for 188 countries. She serves as an elected advisory board member and reviewer for the State of Illinois Maternal Mortality Review Committee for violent deaths.

**Jamila Taylor, Ph.D.,** is the director of health care reform and a senior fellow at The Century Foundation (TCF), where she leads TCF's work to build on the Patient Protection and Affordable Care Act and develop the next generation of health reform to achieve high-quality, affordable, and universal coverage in America. A renowned health expert, Dr. Taylor also works on issues

related to reproductive rights and justice, focusing on the structural barriers to access to health care, racial and gender disparities in health outcomes, and the intersections between health care and economic justice. Throughout her 20-plus-year career, Dr. Taylor has championed the health and rights of women both in the United States and around the world, promoting policies that ensure access to reproductive and maternal health care, including building support for insurance coverage of abortion. Before TCF, Dr. Taylor served as a senior fellow and the director of Women's Health and Rights at the Center for American Progress (CAP), where she led CAP's efforts to advance policies that ensure that women have an equal opportunity to live healthy and economically secure lives. Prior to CAP, she was a senior advisor at Ipas, a global nongovernmental organization dedicated to ending preventable deaths and disabilities from unsafe abortion. She started her career as a congressional staffer in the office of Representative Robert "Bobby" Scott (D-VA) and also worked for the Virginia General Assembly, the AIDS Institute, the National Network of Abortion Funds, and the Center for Health and Gender Equity. Dr. Taylor has published and presented extensively on topics related to reproductive health and rights and public policy. Dr. Taylor graduated with honors from Hampton University with a B.A. in political science. She also holds an M.P.A. from Virginia Commonwealth University and a Ph.D. in political science from Howard University. Dr. Taylor serves on the board of directors for Black Mamas Matter Alliance, March for Moms, and Mamatoto Village (where she serves as the chair of the board). She also serves on the Reproductive Freedom Leadership Council Advocates Advisory Board of State Innovation Exchange.

Brownsyne Tucker Edmonds, M.D., M.P.H. (Planning Committee and Moderator), is an assistant dean for faculty affairs, professional development, and diversity and an associate professor of obstetrics and gynecology and clinical pediatrics at the Indiana University School of Medicine. Dr. Tucker Edmonds earned her bachelor and medical degrees from Brown University, earned an M.P.H. from the Harvard T.H. Chan School of Public Health, completed her residency at Duke University, and earned a master's degree in health policy research from the University of Pennsylvania. Dr. Tucker Edmonds's research interests are in shared decision making and health equity in reproductive health care. She is interested in understanding the impact of race, class, and culture on patient preferences and risk perceptions; physician decision making and counseling; and ultimately, variations in treatment provision and service delivery. Dr. Tucker Edmonds's work primarily focuses on communication and decision making in the management of periviable deliveries. She utilizes qualitative and quantitative methodologies to develop decision support tools and interventions for parents facing this and other preference-sensitive decisions in high-risk obstetrical settings. Her research has been supported by the

Robert Wood Johnson Foundation, The Greenwall Foundation, the Society of Family Planning, and the National Institutes of Health. At the national level, Dr. Tucker Edmonds previously served on the Ethics Committee for the American College of Obstetricians and Gynecologists (ACOG). She now serves on ACOG's Committee on Government Affairs and also serves as the section chair for Indiana ACOG. Dr. Tucker Edmonds was an Anniversary Fellow for the National Academy of Medicine from 2015 to 2017, during which time she served on the authoring committee of the consensus study report *The Health Effects of Cannabis and Cannabinoids: The Current State of the Evidence and Recommendations for Research.* She most recently served on the Committee Assessing Health Outcomes by Birth Setting, which authored the 2020 consensus study report *Birth Settings in America: Outcomes, Quality, Access, and Choice.* 

Saraswathi Vedam, Ph.D., RM, FACNM, Sci.D. (hc), is the lead investigator with the Birth Place Lab and a professor of midwifery in the Faculty of Medicine at The University of British Columbia. Her scholarly work explores experiences of respect, support, discrimination, and mistreatment in perinatal services among people with historically oppressed identities, circumstances, and backgrounds. Over 35 years, her work has set standards for international policy on place of birth, midwifery integration, and equitable access to highquality perinatal care. She also serves as a clinician, educator, and mother to four daughters. Dr. Vedam has coordinated several transdisciplinary and participatory research projects in the United States, including the Access and Integration Maternity care Mapping Study on the impact of integration of midwives on maternal-newborn outcomes, and the Giving Voice to Mothers Study that established significant differences by race, type of provider, and place of birth in experiences of mistreatment by maternity providers. She is currently the principal investigator for Research Examining the Stories of Pregnancy and Childbearing in Canada Today, a national Canadian Institutes of Health Research-funded study examining respectful maternity care across Canada, with a focus on amplifying voices of communities that are seldom heard. Dr. Vedam and her team developed and validated three new personcentered measures, the Mothers Autonomy in Decision Making (MADM) scale, the Mothers on Respect index (MORi), and the Mistreatment by Providers index. In 2017, MADM and MORi received the National Quality Forum Innovation Prize, and they are now being applied in 23 countries to evaluate the quality of maternity care at the institutional, system, and country levels. The data from the application of these tools led Dr. Vedam to develop an interprofessional online course, Dialogue and Decisions, to teach medical, nursing, genetic counseling, and midwifery learners best practices for personcentered decision making and conflict transformation. Over the past decade,

Dr. Vedam convened four national Birth Summits in the United States and chaired the 5th International Normal Labour and Birth Research conference in Vancouver. In 2017, she was named Michael Smith Health Research Institute Health Professional Investigator.

Laurie Zephyrin, M.D., M.P.H., M.B.A., is the vice president for advancing health equity at The Commonwealth Fund. Driven by a passion for transforming health care, she brings her experience as a clinician, health policy maker, and intrapreneur to drive systems transformation. Dr. Zephyrin has extensive experience leading the vision, design, and delivery of innovative health care models across national health systems. From 2009 to 2018, she was the first national director of the Reproductive Health Program at the U.S. Department of Veterans Affairs (VA), spearheading the strategic vision and leading systems change through the implementation of evidence-based policies and programs to improve the health of women veterans nationwide. In 2016-2017, she served as the acting assistant deputy undersecretary, then acting deputy undersecretary, for health for community care. While directing the VA's Community Care program, a key component of the VA's high-performance network with an operating budget of more than \$13 billion, Dr. Zephyrin spearheaded efforts to implement legislation, develop internal governance structures, and address patient outcomes through systemwide optimization of care delivery. As part of the leadership team, she also represented the VA before Congress and other internal and external stakeholders. Dr. Zephyrin is a board-certified clinician. She is a clinical assistant professor of obstetrics and gynecology at the New York University (NYU) Langone School of Medicine (2013-present) and was previously an assistant professor at the Columbia University College of Physicians and Surgeons (2007-2012). She has been named a White House Fellow, Young Global Leader, Robert Wood Johnson Clinical Scholar, and Aspen Health Innovator Fellow. Dr. Zephyrin earned her M.D. from the NYU Langone School of Medicine, her M.B.A. and M.P.H. from Johns Hopkins University, and her B.S. in biomedical sciences from the City College of New York. She completed her residency training at Harvard's Integrated Residency Program at Brigham and Women's Hospital and at Massachusetts General Hospital.

